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Assessing Palliative Care Policies in Africa:

Implications for Paediatric Palliative Care

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Part A: SECTION 0: PREAMBLE

To the memory of my late Father

Abstract

Around the world, there are millions of children who need palliative care from the moment they are diagnosed with life-threatening and life-limiting illnesses, yet very few children have access to palliative care services. In many African countries, where palliative care is still new, many children with chronic illnesses continue to experience needless pain and suffering. The World Health Assembly Resolution 67.19 made a clear call for governments around the world to implement palliative care policies. Such policies should support the "comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels of care". However, despite these frequent calls, no specific policies target the provision of paediatric palliative care in Africa.

This dissertation consists of three parts.

Part A is the study protocol, which consists of the introduction and the study methodology. The study is qualitative in nature and it adopted the Walt and Gilson framework for extraction of data and analysis of palliative care policies in Africa. The study used publicly available policy documents, which were identified and obtained from government websites, international agencies' websites and through communication with palliative care experts. An excel spreadsheet was used to extract data, which was analysed thematically.

Part B is a literature review of available published and unpublished work pertaining to paediatric palliative care in Africa. It provides the historical background of palliative care

and defines palliative care and paediatric palliative care as well as exploring the general literature on paediatric palliative care, and the evidence on the existence of palliative care policies in Africa.

Part C is a journal manuscript. It follows the structure and guidelines of the journal of the Health Policy and Planning. The manuscript begins with introduction and the study methods. Further, the study used publicly available policy documents on palliative care in Africa published from 2002 until 2018. An appropriate conceptual framework was chosen, and the results of the policy analysis are provided and followed by the discussion section and conclusions.

The study findings indicate that few palliative care policies exist in Africa, and children's palliative care needs are not adequately included and addressed. The findings further show that there was no single policy targeting paediatric palliative care, and children were included among the larger population. As such, palliative care needs were not sufficiently addressed. Only three policies (South Africa, Zimbabwe, and Malawi) clearly address paediatric palliative care needs. The study, therefore, argues that for children with life-threatening and life-limiting conditions to be free from pain, African governments need to formulate specific policies that will guide the provision of paediatric palliative care.

This study is likely contribute to policy making processes, acts as a reference document for academics and students and provides an advocacy tool for activists, nongovernmental organizations (NGOs), and civil society organizations (CSOs) working on children's

welfare and human rights issues more broadly. Further, the findings of the study may contribute to formulating specific palliative care policies for children, particularly in African countries that lack such policies.

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Plagiarism declaration

I, Epiphania Ngowi (NGWEPI001), hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Signed by candidate

Signature:

University of Cape Town, Feb 2020

Contents

Abbreviations

APCA	African Palliative Care Association
CPC	Children's Palliative Care
CDC	Centre for Disease Control and Prevention
HPCA	Hospice Palliative Care Association of South Africa
HAART	Highly Active Antiretroviral Therapy
ICPCN	International Children's Palliative Care Network
MOH	Ministry of Health
MOHSW	Ministry of Health and Social Welfare
NCD	Non-Communicable Diseases
NPFSPC	National Policy Framework and Strategy for Palliative Care
PC	Palliative Care

PPC	Paediatric Palliative Care
PMTCT	Prevention of Mother-to-Child Transmission
WHO	World Health Organization
USAID	United States Agency for International Development
UNICEF	United Nations International Children’s Emergency Fund

Definition of key terms

Palliative care	The World Health Organization (WHO) defined palliative care as "an approach which improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual problems" (World Health Organization 2002, p. 84).
Paediatric palliative care	Refers to "the active total care of the child's body, mind and spirit, and also involves giving support to the family…" (World Health Organization 2010). It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease *(*World Health Organization 2010*).*
End-of-life care	Is described as the care a person with chronic illness receives during the last stage of their life.
Life-threatening conditions	"A life-threatening disease is a disease that is potentially fatal, likely to result in imminent death" (Meiring 2011).

Life-limiting conditions	These are chronic conditions or illness for which there is no reasonable hope of cure and death is inevitable, either in childhood or early adulthood (www.icpcn.org/faq/). It may not be immediately life threatening but it reduces the quality and or quantity of life of an individual (Meiring 2011).
A child	The United Nations convention of human rights defined a child as a person under the age of 18 (https://www.unicef.org/crc/files/Guiding_Principles.pdf.)
Hospice care	Hospice care is described as a model for delivery of palliative care for patients at the end of life when curative or life-prolonging therapy is no longer beneficial (Meier et al. 2017).
Health policy	A health policy is defined as decisions, plans, and actions undertaken to achieve specific health care goals within a society (http://www.who.int/topics/health_policy/en/.)

Part A: PROTOCOL

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Introduction

Worldwide, access to paediatric palliative care (PPC) remains a public health challenge, particularly in resource limited settings (Downing et al. 2018). In 2017, it is estimated that more than 21 million children facing life-threatening and life-limiting diseases need palliative care annually worldwide. Of these, more than 8 million require some degree of specialized care (Connor et al. 2017). While in theory, children and families facing a life-threatening or life-limiting illness may benefit from improved quality of life and end-of life care, PPC services are not widely available in low-and middle-income countries (LMICs), particularly in Africa (Crozier and Hancock 2012). This lack of services is attributed to several factors such as the absence of comprehensive palliative care policies that integrate palliative care at all levels of care; lack of knowledge of palliative care among health workers; misconceptions pertaining PC; lack of funding; as well as poor access to pain medications (Rhee et al. 2018; Downing et al. 2018; El Ansary et al. 2014). To address the above challenges, there have been several efforts at national and international level to improve access to PPC. One such initiative is the International Children's Palliative Care Network (ICPCN) established in 2005, which aims to promote access to PPC and their families through information sharing, networking, education, research and advocacy (Marston et al. 2013). The ICPCN was established with the belief that

> *…children with life-threatening or life-limiting conditions deserve relief of their suffering and the best possible quality of life, combined with the*

> *realization that children's palliative care development had lagged far behind that of adults in terms of service provision and education.*
>
> (Marston et al. 2013, p. 308).

The fundamental idea behind the formation of the network was that different countries with different backgrounds and challenges (resource-rich or poor) could learn from each other (Marston et al. 2013). In addition to ICPCN, several other similar initiatives exist (see Inbadas et al. 2016: e8). Despite these initiatives, access to PC for millions of children in-need remains a low priority in many developing countries, particularly in Africa.

A brief history of palliative care

The history of palliative care dates to 1967 when the first modern hospice care was introduced, through the initiative of Dame Cecily Sunders, and the opening of St. Christopher's hospice in the United Kingdom (Luck 2014). Fifteen years later, the first children's hospice care was opened in 1982 in England to provide respite care for children with life-threatening illnesses (Foster 2007).

In Africa, hospice care started in early 1970s, when such services were first introduced in Zimbabwe and South Africa (Clark et al. 2007). For other African countries, the development of palliative care and hospice care began in the early 1990s. For instance, in both Swaziland and Kenya, hospice care started in 1990, followed by Botswana, Tanzania, and Zambia in 1992, Uganda (1993), Nigeria (1996), Malawi (1997) and Egypt (2001) (Clark et al. 2007).

Both “palliative care” and “hospice care” are provided to patients with chronic illnesses in their last stage of life, and these terms were used interchangeably until the 1980s (Foster 2007). However, in many settings these two forms of care are distinct and are provided in different settings (Davis et al. 2015). Today, the provision of palliative care is no longer limited to “end-of-life care” or cancer patients, as it is now applied to all patients with complex, chronic or life-threatening illnesses (World Health Organization 1990; Lutz 2011). Evidence shows that palliative care is considered effective for patients with life-threatening or life-limiting conditions when administered early, particularly from a time a person is diagnosed with the condition (Abraham et al. 2002; Albert et al. 2002).

Defining palliative care and paediatric palliative care

The first definition of palliative care was published by the World Health Organization (WHO) in 1986. However, due to an increasing burden of chronic diseases, the definition was amended in 2002. Today, palliative care is officially defined as:

> *… an approach which improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual problems.*
>
> (World Health Organization 2002, P. 84).

When compared to hospice care, the above definition is more comprehensive as it includes a wide range of palliative care services and put more emphasis on symptom management as well as holistic care of patients and family facing a life-threatening illness (Crozier and Hancock 2012).

Conversely, PPC is defined as “the active total care of the child’s body, mind and spirit, and also involves giving support to the family…” (World Health Organization 2010). It normally begins when a patient is diagnosed with an illness and continues regardless of whether a child receives treatment directed at the disease (World Health Organization 2010). Even though PPC is closely related to adults’ palliative care, children’s palliative care goes beyond managing pain and incorporates close attention to the child’s growth and development, nutrition, schooling, relationships, hopes, fears and wishes (Breemen 2009). Palliative care for children also includes a wide range of chronic diseases and a child may need generalized or specialized palliative care or a combination of both depending on the diagnosis.

Research shows that not all children with conditions requiring palliative care will need access to specialist care because PC can be provided by other primary health care providers (Connor et al. 2017). However, children with more complex conditions need access to specialized care (Connor et al. 2017). Yet, the provision of these services further depends largely on the availability of resources in the country in question.

The state of paediatric palliative care in Africa

Most African countries are yet to institute the provision of PPC services. Although children with chronic conditions may require some form of PC, these services are limited and very few children with life-limiting conditions and their families have access. A detailed systematic review conducted to assess the provision of PPC around the world (Knapp et al. 2011; Lynch et al. 2011) found that of the 53 African countries, 81% had no known children's palliative care activity, and 43% did not have known palliative care activity at all, either for adults or children (Lynch et al. 2011). The review established that in North Africa, only four countries – Morocco, Egypt, Sudan and Tunisia – had isolated palliative care service provision, however, none of them offered generalized palliative care services to individuals who require these services (Lynch et al. 2011).

According to El Ansary et al (2014), in Africa, children requiring palliative care services receive such care late and very few of them has access to care because of lack of national policies that guide the development and provision of PC services. Other challenges facing PPC in Africa include a lack of understanding of disease processes in children; poor access to medications such as opioids; myths concerning children's perception of pain; and poverty (Mwangi-Powell et al. 2011).

Available evidence shows that HIV/AIDS and cancer are among the most common chronic childhood diseases in Africa (Amery et al. 2009). In 2012, the Joint United Nations Programme on HIV/AIDS estimated that there were 1.8 million children age 0-14 years with HIV in Sub-Saharan Africa (UNAIDS 2012). While there is a lack of data regarding

children with cancer in Africa, available estimates show that more than 80% of cancer diagnoses and 90% of cancer deaths occur in developing countries (Cancer Research UK 2009).

Currently, about 49% of children in need of palliative care around the world live in Africa (Worldwide Palliative Care Alliance 2014; World Health Organization, 2014). However, there is a huge gap between the need for palliative care and the services available for children requiring such care. Although most studies estimating the need for PPC are based on mortality data for chronic diseases, the most recent data shows that the number of children in need of specialized care was high in LMICs, particularly in Africa. This may be attributable to the high rate of HIV/AIDS. Table 1 below shows the estimated need for PPC in six African countries.

In 2012, the United Nations International Children's Emergency Fund (UNICEF), reported that only about 5% of children in need of palliative care have access to such services in South Africa and Zimbabwe, while only 1% of children have access to PPC in Kenya (UNICEF and ICPCN 2013).

Table 1: Need for PPC in Africa

Country	**Population**	**Prevalence of conditions requiring PC**	**Total need**	**Specialized need**

Egypt	78,080,000	580,731	391,135	147,311
Ethiopia	87,100,000	846,272	543,911	217,409
South Africa	50,900,000	925,622	549,778	207,909
Kenya	40,910,000	678,966	425,014	166,888
Malawi	14,901,000	349,696	211,353	80,887
Zimbabwe	13,080,000	356,465	210,849	79,465

Source: (Connor et al. 2017).

As Table 1 above illustrates, African countries with a large population also have the highest number of children requiring palliative care. For instance, Ethiopia has a population of 87,100,000 million people and the total need of children requiring palliative care is estimated at 543,911, of which 217,409 require specialized care. In South Africa, the estimated number of children requiring access to PPC is 549,778 and of these 207, 909 need specialized palliative care.

Over the past few years, the number of African countries providing PC has increased (Fraser et al. 2017). Nonetheless, the development of PPC remains significantly low despite the increasing need (Grant et al. 2005). For instance, only six countries (Kenya, Malawi, South Africa, Tanzania, Zimbabwe, and Uganda) have developed some specialist services for children (Downing et al. 2010). At the same time, most PPC services are

constrained by the lack of finances, health professionals and essential medicines (Harding and Higginson 2005).

Contrary to the situation in African states, the provision of PPC in developed countries has progressed significantly. A systematic review on PPC around the world found that Europe has well-developed PPC services compared to other regions in the world (Knapp et al. 2011). However, even within the developed countries, differences remain in the provision of PPC. For instance, a study on Europe indicates that in the United Kingdom (UK), PPC is better developed compared to other countries in the region (Dangel 2002).

In an attempt to reverse the PPC situation in Africa, there have been several initiatives to improve the provision of palliative care, including the Cape Town Declaration, which was launched in 2002. The declaration was the result of the conference attended by palliative care professionals from twenty-eight African countries. The trainers were given "an opportunity to develop a regional strategy to raise awareness of and increase investment in palliative care as a sustainable and integrated aspect of health delivery systems" (Mpanga Sebuyire et al. 2003, p. 342). The declaration recognized that palliative care is the right of every adult and children with life-threatening conditions and it should be included into the national health care strategies (Mpanga Sebuyire et al. 2003).

This declaration led to the formation of the African Palliative Care Association (APCA) in 2004, which aims to improve information, integration, and evidence. The association highlights that individuals with life-threatening illnesses, including children should have

access to affordable and culturally appropriate palliative care (Grant et al. 2011). Despite all these efforts, African countries still need to invest in the strengthening of their health systems and integrating PC in their national health policies to improve the development and access to PPC.

Study rationale

The proposed study will focus on palliative care policies addressing both adults and children because evidence shows that most existing policies focus on adults, but also include some references to the care of children (Hospice Africa 2008). According to Brown et al (2014), palliative care services in developing countries, particularly in Africa, may be based on mixed care models, in which systems for adults may also accommodate a small number of children in need of such care. In addition, there are several misconceptions regarding children's palliative care, particularly on the conditions requiring palliative care. These misconceptions indicate the need to have concrete efforts in place to advocate for palliative care for children.

Although PPC is closely related to that of adults, in practice the provision of care to children is quite different. This is because PPC needs to consider age, the underlying illness and more importantly, the fact that children's perception of their condition, dying and ultimate death are significantly influenced by their developmental age (Lück 2014; Marston and Chambers 2012). For these reasons, Marston and Chambers (2012) have argued that children have diverse and complex diseases that require special attention.

Therefore, this thesis aims to explores the existing palliative care policies in Africa and examines whether such policies address the needs of children. Within the African context, this review is considered critical since there is no study that has investigated PPC policies on the continent. By documenting what policies exist and assessing the extent to which such policies address children's needs, this study will contribute important lessons that can aid policy makers with the design of specific policies to guide children's palliative care in Africa.

Purpose of the study

There is a paucity of knowledge regarding the situation of PC policies in Africa. Most studies focused on adult' palliative care and little attention is given to PPC. This study will therefore contribute new insights to the emerging literature on PPC. It is anticipated that the findings of the study will inform policymaking processes, act as a reference document for academics and students and provide an advocacy tool for activists, nongovernmental organizations (NGOs), and civil society organizations (CSOs) working on children's welfare and human rights more broadly. In addition, the findings of the study may contribute to the formulation of specific palliative care policies for children, particularly in African countries where such policies are not in place.

Study question

This policy analysis will be guided by the following research questions:

Primary question

Are there existing palliative care policies in Africa and do these adequately address paediatric palliative care needs?

Sub-questions

What policies exist for guiding palliative care?

Do they include paediatric palliative care needs and, if so, how?

To what extent do these policies address paediatric palliative care needs?

Study aim

This study aims to explore the current situation of PPC in Africa by examining the existing palliative care policies and assessing whether these include and sufficiently address PPC needs.

Methodology

Study approach: Policy Analysis

Health Policy Analysis (HPA) is described as a "multi-disciplinary approach to public policy that aims to explain the interaction between institutions, interests and ideas in the policy process" (Walt et al. 2008, p. 307). According to Buse et al (2008), policy analysis plays

an important role in providing technical evidence for future policy formulation and implementation. One of the goals of health policy analysis is to measure the effect that a certain policy has or will have on people (Collins 2005).

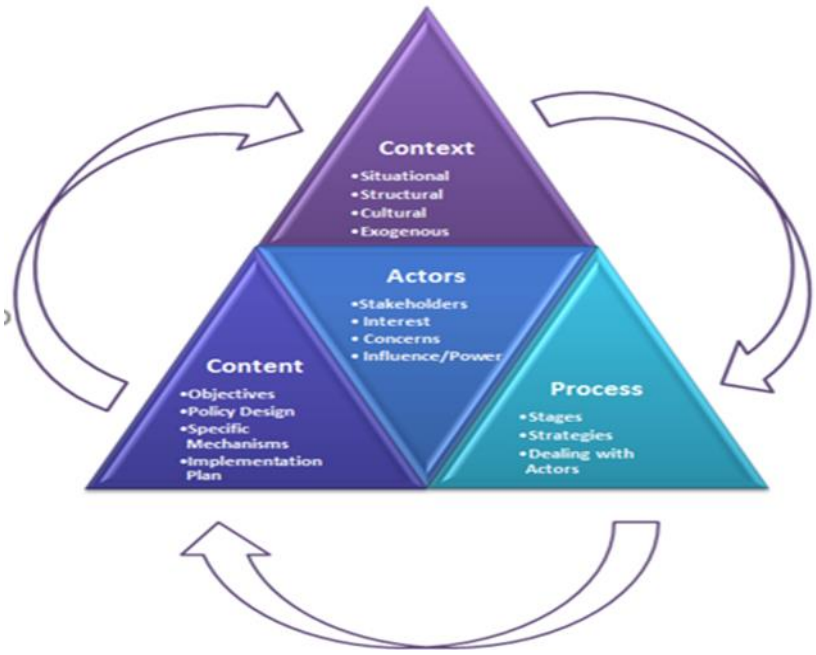
A policy analysis can be done retrospectively or prospectively. A retrospective policy analysis looks back at why or how a policy is formulated, its content, and whether or not the policy achieved its desired goals. A prospective policy analysis is usually done to generate insights to inform the preparation and formulation of a particular policy (Buse et al. 2005).

This study employed a retrospective policy analysis of palliative care policies in Africa to assess whether they include and address PPC. Special attention is directed to the policy content, which is described as the body of the policy. The content of the policy is determined in terms of the problem it aims to change, its programmes, projects, actions or specific activities, targets, and resources required (Araujo et al. 2001). Collins (2005) argues that in reviewing policies one should specifically identify at which part the policy the analysis will be directed. Whether the analysis will focus on policy process or policy content needs to be clarified. Collins further maintains that the policy process analysis focuses on policy formulation while the analysis of policy content focuses primarily on the elements of the policy (Collins 2005). In addition, an analysis of policy content should examine and explore a substantial policy issue and explores different options to address it (Ham 1990).

Analytical framework

To ensure proper analysis of the policy documents, this study is informed by Walt and Gilson's (1994) framework. According to Walt and Gilson (1994) the framework highlights ways of understanding the aspects and forces that influence why and how policies are initiated, formulated, negotiated, communicated, implemented, and evaluated (Walt and Gilson 1994). The framework incorporates four components: context, content, process, and actors as shown in Figure 1.

Figure 1: The conceptual framework



Source: (Walt and Gilson 1994).

The context of the policy refers to the systemic factors which include situational, structural, cultural and international (Letcher 1979) factors, while the policy content refers to the policy goals or objectives, policy design and the implementation plan. The process of the policy relates to the set of decisions as well as non-decisions made by interest groups such as policy actors, who are the individuals or groups and organizations involved in making the policy. According to Gilson (2008, p 2), policy actors are the 'heartbeat' of the policy and the policy process because of the influence they have on policy development. This study adopted the policy triangle framework not only because it is the most used framework (Gilson and Raphael 2008), but because it is appropriate to address the research questions. As Ostrom (2007) argues, the use of a framework in analysing policies enables researchers to identify policy elements as well as the relationships between them.

The study did not look at all four components of the triangle in detail. The four dimensions were used as themes to interrogate policies and identify how policies have addressed process, which actors have been involved and at which actors is the policy targeted. Further, the study also derived the context in which the policies were developed from the literature and gave more detailed analysis on the policy content. Understanding how palliative care policies address the needs of children required an understanding of the policy content and how it interacts with other components of the health policy triangle.

As Figure 1 illustrates, each component of the framework is relevant in and of itself; the components also interact with each other and it is important to analyze them together rather than in isolation.

Sources of data

This study is based on a documentary review of all relevant policy documents addressing palliative care in Africa. These sources include policies, reports, position papers and meeting proceedings. The main reason for relying on unpublished documents is because there is little published evidence-based research for policies guiding provision of palliative care in Africa. As Merriam (1998, p.118) explained, reviewing different types of documents can enable investigators to "uncover meaning, develop understanding, and discover insights relevant to the research problem".

Documentary review was conducted by searching for, reviewing, and analyzing documents (Walsh 2014). The advantage of documentary review is that it is an efficient method, especially during data analysis, because it does not require time and resources devoted for producing primary data through surveys or experimental methods (Bowen 2009). The documentary review also provided information on programs that were not be directly observable, and highlights issues that are not noted by other methods such as surveys (Center for Disease Control 2009).

Assessment of the policy content

Although there is no gold standard for assessing health policies, the contents of the retrieved policy documents were assessed by asking the following questions that were taken from policy documents from high income countries (HICs) which are Ireland, United Kingdom, and Australia. These countries were selected because they have made progress in the development and provision of paediatric palliative care services. For example, the United Kingdom have been praised for providing several key documents that are instrumental to paediatric palliative care needs. One of the important document include key recommendations for care of children with life-threatening and life-limiting conditions as well as the classification of conditions requiring palliative care for children which was developed by the Association for Children with Life-threatening or Terminal Conditions and their families (ACT) in 1997. These questions include:

- Does the policy target children, adults, or both?
- Does the policy adhere to the definition of PPC provided by the World Health Organization?
- Are the policy's aims and objectives clear?
- Does the policy define pathways to care (e.g. from tertiary hospital, how do you know there is continuity of care?)
- Is the policy child- and family-centered in its approach to palliative care?
- Does the policy include multidisciplinary teams?

- Does the policy include care that is provided in a preferred setting?
- Does the policy provide for education programmes?
- Is there enough health workforce we need for PC?
- Are there strategies that support health care providers and care givers?
- Does the policy include a budget?
- Does the policy talk about governance and leadership?
- Does the policy have monitoring and evaluation plan?
- Does the policy have an implementation plan?

Data extraction

Data from relevant policy documents was extracted and summarized using data extraction forms designed by the researcher. This involved carefully assessing the policy documents while taking note of the appropriate evidence to be incorporated in the study.

To answer the sub- research questions, the following steps were taken:

Question 1 and 2

What policies exist for guiding palliative care?

Do they include paediatric palliative care needs and, if so, how?

A thorough database search was performed to identify any possible policies that exist based on the inclusion criteria set by the researcher. Each policy document deemed relevant was extracted using the data extraction sheet (Appendix 1). Extracted information includes:

- The name of the country
- The title, author, and year of publication of the document
- Data sources

To assess whether the policy documents include paediatric palliative care needs, data extraction included the following:

- The objectives of each policy document
- Target group (adults or children or both)
- Key information about the implementation plan if specified in a policy document.

Question 3

To what extent do these policies address paediatric palliative care needs?

This question was addressed by analysing the identified policy documents that included paediatric palliative care. Two data extraction sheets were used to extract data based on the policy framework for the study.

- Firstly, data on policy context, process and actors that were involved in the policy will be extracted (Appendix 2).
- Secondly, data on policy content which is the main focus of the study was guided by the criteria mentioned earlier. To better guide the analysis of this study, the assessment questions were drawn from some well-developed PPC policies from HICs documents from Ireland, UK, and Australia. (Appendix 3).

All extracted information was entered into an Excel spreadsheet. The use of data extraction sheets allowed proper arrangement of the retrieved information and provided good visual assessment, minimizing errors and the bias of the review as well as providing a detailed data registry for analysis (Higgins and Green 2008; Tranfield et al. 2003).

Searching for policy documents

Documents reviewed for the study were identified and accessed through several procedures. First, a comprehensive search of electronic databases was performed to identify both published and unpublished (grey literature) documents. The following steps were taken:

- First, all documents on current policies for palliative care for both adults and children were purposefully identified based on eligibility criteria set by the researcher[1].
- Second, policy documents that are difficult to retrieve were accessed by contacting health service administrators and regional networks such as the African Palliative Care Association (APCA) and the International Children Palliative Care Network (ICPCN).

Multiple searches were conducted using different search terms in different databases. Combinations of search terms and synonyms are central to improving the effectiveness of literature searches (Bown and Sutton 2010). The research question guided the selection of keywords to be used by using a pre-specified search strategy in all databases. For instance, Boolean operators such as “AND” and “OR” were used to combine the selected keywords (Akobeng 2005). The search terms were developed with the help of UCT librarians with expertise in using online databases and involved five steps. The first step included terms relating to ‘palliative care’, ‘hospice’, ‘end-of-life’, ‘respite care’ and ‘care of dying’; the second step consisted of search terms such as ‘paediatric’, ‘pediatric’, ‘child’, ‘children’; the third step included ‘adults’ ‘adult’; the fourth step included ‘non

[1] Selection of relevant documents included in the review was determined during the second phase of the study that is literature review.

communicable diseases' 'long-term health conditions' 'chronic diseases'; and the fifth step included 'policy' or 'policies'.[2]

Databases searched include:

- PubMed, PsychINFO, Google and Google scholar.
- Reports and other policy documents were searched using government websites such as the Ministry of Health and Social Welfare (MOH/MOHSW), departments of health and international agencies such as the World Health Organization (WHO), United Nations International Children's Emergency Fund (UNICEF), and United States Agency for International Development (USAID), Alliance for Health Policy and Systems Research, African palliative Care Association (APCA) and the International Children's Palliative Care Network (ICPCN).
- Google search was done to search for government policies as most policy documents included in this study are unpublished. Key terms that were used include 'palliative care' 'paediatric palliative care', 'health policy', 'non-communicable diseases', 'long-term health conditions' combined with 'Africa'.

[2] A complete search terms was finalized in the second phase of the study.

Since one of the limitations of documentary review is the lack of sufficient information to answer the research question (Bowen 2009), the researcher did whatever possible to extract adequate information to respond to the research question. This includes sending emails to the key informants and other important people that may have access to policy documents, as well as asking them for additional information that is not in the selected policies, particularly in countries for which policy documents are not accessible from online sources.

Inclusion and exclusion criteria

Inclusion criteria were established prior to conducting searches for the relevant documents and specified the type and characteristics of documents to be included in the analysis.

Policy documents that were eligible for the review included:

- Any palliative care policy that targets adults or children or both.
- Policies on non-communicable diseases (NCDs) and policies on long-term health conditions (LTHC) or chronic diseases as these may contain aspects of palliative care.
- Policies published from 2002 till 2018.

Policy documents were excluded if:

- They were not published in English. This is to avoid possible difficulties in translation and to save time. However, the presence of the policy is documented, but the language and resource constraints did not allow us to analyze documents that are in French, Arabic or Portuguese, which are the languages most likely to emerge.

Selection of documents

Based on the inclusion and exclusion criteria identified above, the selection of the policy documents involved screening them to determine if they meet the eligibility criteria. Titles of the policy documents were identified and retained for further screening to remove all documents which are duplicate or irrelevant. Since most of the documents included are unpublished, most of them lack abstracts (Benzies et al. 2006), which made it difficult to transfer and organize them using software such as RevMan or Endnotes. Therefore, the retrieved documents were transferred to an Excel spreadsheet. All full-text documents that were relevant for the study were organized in a table and sent to a second reviewer to assess them independently and to assess their eligibility for inclusion. A table describing the features of all included and excluded documents was then displayed for final review.

Data Analysis

Data was analysed using thematic approach informed by Braun and Clarke (2006). Thematic analysis allowed for clear identification of prominent themes (Dickson-Woods et al. 2005) that arose from the policy documents. First, based on themes and subthemes

already identified by the researcher, thematic analysis was used to identify subthemes from the policy documents through reading and re-reading of the policy documents critically as well as looking for key words that emerged from them. Second, the retrieved information was then organized by assessing how they fit in the policy triangle, which incorporates content, context, process, and actors. In the analysis of policy context, the study looked for specific sub-themes on what the policy document provided regarding the macro context, such as the politics, finances, and human resources as well as the macro context of policy implementation. In the policy process, the analysed information included how the policy process unfolded, how they went about it, whether they drew on evidence, and which groups were involved. Also, the analysis assessed the actors that were involved in developing the policy and those for whom the policy has implications.

Study Limitations

Because documents for the review were selected purposively, this may have introduced bias, as only those documents that support the framework would have been selected (Hsieh & Shannon, 2005). Further, including only policy documents published in English may have also introduced bias and limited the scope of the review, as documents published in other languages could have provided relevant evidence on palliative care policies in Africa.

Ethics

There is no ethical approval required for this review since it only involves reviewing existing, publicly available, policy documents. However, the review proposal was submitted to the University of Cape Town, Faculty of Health Science Dissertations Approval Committee for approval before proceeding with the research.

Dissemination

The findings of the review will be submitted to the University of Cape Town as a partial fulfilment towards the Degree of Masters in public health. Also, a peer-reviewed journal will facilitate the dissemination of the study findings. Further, it is expected that the study findings will be valuable given the existing limited literature on paediatric palliative care policies in Africa.

Table 1: Study timeline

Component	**Activity**	**Date**
Part A: Protocol	Subject formulation	April 2017
	Draft	May – July 2017
	Edits	August 2017

	Final edits	Oct. 2017
Part B: Literature Review	Research	May 2017- 2018
	Draft	Nov. 2017
	Edits	July 2018
	Final edits	Aug 2019
Part C: Journal Article	Draft	Aug 2018
	Edits	Oct 2018
	Final edits	May- October 2019
Submission	Intention to submit	Nov 2019
	Submission	Feb 2020

Budget

This study was done as part of the fulfilment of the Master's degree in Public Health and it was self-funded by the main investigator and therefore there were no conflicts of interest.

Table 2: Study budget

Item	**Cost (Rands)**
Off campus internet cost	3000
Stationeries (pen, notebooks, makers, papers)	500
Printing	1000
Total cost	4500

Source: Author

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Appendixes

Data extraction templates

Appendix 1: Summary of the policy documents

	Date published							
Document no:		**Country**	**Name of the document**	**Source of the document (where documents was obtained)**	**Type of the document (e.g. Policy, plan, guideline, etc.)**	**Goals/ objectives of document**	**Target population (e,g. adults & children or specific to children)**	**Implementation plan**
1								

2								
3								
4								
5								
6								
7								
8								

Appendix 2: Data extraction template on policy context, process, and actors

Document 1	**Country**	**Year**	**Status of the policy (draft/ approved)**	**Policy context**		**Policy process**		**Policy Actors**		
				Macro context	**Micro context**	**Policy development**	**Use of evidence**	At political level	Service level	Community level

Appendix 3: Policy content data extraction sheet (excel spreadsheet was used)

Document 1

Country	**Documents**	**Status of the document**	**Theme: Policy contents**					
			Sub-themes					
			Definition of PC, needs assessment	**Yes/No**	**Health workforce team**	**Yes/No**	**Implementation plan**	**Yes/No**
			Does the policy target children, adults or both?		Does the policy include multidisciplinary teams?		Does the policy provide education programmes?	

			Is the definition of PPC in line with WHO?		Are there enough health workforce we need for PC?		Does the policy provide methodology determining the number of children PC services?	
			Are the aims and objectives clear?				Are there strategies to support health care providers and care givers?	
			Are the objectives measurable?				Does the policy include a budget?	
			Is the policy child- and family-centered?				Does the policy talk about governance and leadership?	

			Does the policy define pathways to care?				Does the policy have monitoring and evaluation plan?	

Part B: LITERATURE REVIEW

Table of contents

Introduction

Palliative care has been described as an important component of care that should be available to all children with life-threatening and life-limiting conditions, “regardless of where they live, their culture, nationality, or stage of sickness” (Downing et al. 2015(a), p. 2). Yet, in many parts of the world, there is an overwhelming need for paediatric palliative care (PPC) (International Children’s Palliative Care Network 2019). Millions of neonates, infants, children, and adolescents with chronic conditions need palliative care (PC) from the moment they receive a diagnosis of a life-threatening or life-limiting illness worldwide (Royal College of Nursing 2018, Connor et al. 2017). An estimated 2.5 million children die every year of conditions requiring palliative care and most of them are in low- and middle-income countries (LMICs) (Knaul et al. 2017).

Currently access to PPC is limited or unavailable in many parts of the world, particularly Africa (Downing et al. 2015 (a); World Health Organization 2018). Evidence shows that in places where such care is available, they tend to focus more on adults (Downing et al. 2010). For example, whilst more than 50% of child deaths occur in developing countries, mostly in Africa (World Health Organization 2003), less than 5% of those in need of palliative care receive such service (Downing et al. 2015(a)).

In Africa, particularly, there is a great need of PPC because of the increasing burden of communicable and non-communicable diseases (NCDs) (Downing et al 2018). The NCDs are projected to increase significantly by 2030 (World Health Organization 2013) and so will the need for PPC. Therefore, as the demand for PPC increases worldwide, improved access to children’s palliative care services is necessary, and particularly in African countries where PC is inadequate and underfunded (International Children’s Palliative Care Network 2019; Rhee et al. 2018).

Developing and formulating policies to guide PC services have been identified as fundamental components to support the provision of palliative care (Worldwide Palliative Care Alliance 2014). However, research pertaining to policies to guide, develop and provide palliative care in Africa is limited and therefore warrants further investigation. This literature review aims to assess what is already known about palliative care in Africa, particularly PPC and to review the evidence on palliative care policies specifically for children.

Method

Search strategy

A literature search was performed to assess what is already written about palliative care policies in Africa generally, and more specifically about paediatric palliative care. The search strategy and key concepts relating to palliative care were developed to understand how child palliative care needs are included in a particular policy document. This informed part C of the study which is policy analysis. It involved reading grey and published literature. However, in part C only grey literatures (policy documents) were used for analysis. Databases that were searched included: PubMed, Psych INFO, Google, and Google Scholar. Further, reports and policy documents were searched using government websites such as the Ministry of Health and Social Welfare (MOH/MOHSW), health departments and international agencies such as the World Health Organization (WHO), United Nations International Children's Emergency Fund (UNICEF), and United States Agency for International Development (USAID), Alliance for Health Policy and Systems Research, African palliative Care Association (APCA) and the International Children's Palliative Care Network (ICPCN). In addition, policy documents that were difficult to obtain

through a desk-based review were requested via email communication from professionals and/or people working in the field of PC in their respective countries. Key terms used to search for the documents were arranged in five groups (see Table 1).

Table 1: Literature review and policy documents search terms

Groups	Key terms	Context
Group 1	'palliative care', 'hospice', 'end-of-life', 'respite care' and 'care of dying'	Africa
Group II	'paediatric', 'pediatric', 'child', 'children'	
Group III	'adults' 'adult'	
Group IV	'non communicable diseases' 'long-term health conditions' 'chronic diseases'	
Group V	'policy' or 'policies'	

Inclusion and Exclusion criteria

The study included only articles and policy documents published in English and from 2002 till 2018 (Appendix 2). This timeline was selected because most African states started to formulate PC related initiatives including policies after this period. For example, the key momentum for African countries to embark on PC was after the release of the Cape Town Declaration on Palliative Care in 2002. Further documents include:

- Any palliative care policy that targets adults or children or the larger population
- Policies on non-communicable diseases (NCDs) and policies on long-term health conditions (LTHC) or chronic diseases as these may contain aspects of palliative care.

Policy documents were excluded if they were not published in English. This was to avoid possible difficulties in translation and to save time. However, the presence of the policy was documented, but the language and resource constraints did not allow us to analyse documents that may be in French, Arabic or Portuguese, which are the languages most likely to emerge in Africa.

Adult palliative care versus paediatric palliative care

Since this study is interested with PPC it is essential to make a distinction between adult and child palliative care because they are different but closely related in many ways. For instance, although the first definition of PC existed since 1986, it was not until 1998 when the WHO provided a comprehensive definition of palliative care for children that is appropriate to address the needs of children with life-limiting and life threatening illnesses. The previous definition of PC focused largely on cancer patients, however, as the chronic illnesses increased the WHO saw a need to update its definition in 2002 that included other illnesses and drew attention to family involvement (World Health Organization 2010).

Palliative care is described as an approach that intends to enhance the quality of life of patients enduring pain because of a long-term illness, and their family by preventing suffering and pain through early identification of the disease, reducing pain as well as accurate assessment and management of pain, and other problems, physical psychosocial and spiritual (World Health Organization 2002; p. 84).

PPC refers “to the active total care of the child’s body, mind and spirit, and also involves giving support to the family” (World Health Organization 1998.) In countries where services are in place, the provision of PC usually begins early when a child is diagnosed with an illness and continues regardless of whether or not a child receives treatment directed at the disease (World Health Organization 1998). An effective PC requires not only a multidisciplinary approach but also one that makes use of family and all available community resources. Palliative care can be provided in available community health centers as well as tertiary care facilities and children’s own homes (Knapp et al. 2012; World Health Organization 1998).

Although PC for children is closely related to adults’ palliative care, children’s palliative care is unique as it incorporates close attention to child’s growth and development, nutrition, education, relationships, hopes, fears and wishes (Breemen 2009). As the WHO explains “children are not little adults”, therefore full attention should be paid, particularly to their physical, developmental, psychosocial, ethical, and spiritual as well relational phenomena that are unique to them (World Health Organization 2018, p. 7).

Whilst the definition of palliative care for both adults and children emphasize that PC should be provided early from the point of diagnosis, in practice, palliative care services are provided at the end-of-life in many parts of the world (Hupcey et al. 2009). As such, adults have more likelihood of receiving PC services than children (Institute of Medicine 2003), though children are reported to be more resilient and more likely to require such care for longer periods than adults (Connor et al. 2017). For example, a study that investigated the perception of nurses about palliative care in Nigeria found that 90.2% of nurses believed that PC is about the care of patients who are dying (Fadare et al. 2014). The study further established that some of the health care providers believe

that palliative care is mainly for cancer patients while others understood that palliative care is the same as rehabilitation medicine (Fadare et al. 2014). This confusion is mainly because of “lack of awareness of what palliative care entails, the impact it can have, and insufficient acknowledgement of the need for PPC, both at the community and the policy levels” (Downing et al. 2018, p. 5). As such, the United Kingdom (UK) based Association for Children with life Threatening (ACT) life limiting conditions proposed four different categories of health conditions of children requiring PC (see Table 2).

Table 2: Health conditions requiring PPC

Categories	**Health conditions**
Category 1	Life threatening conditions where cure is possible but may fail. For example, Acute Lymphoblastic Leukemia, TB, Malnutrition.
Category II	Conditions for which premature death is inevitable, but long periods of wellness with reasonable quality of life are possible because of available treatments, for example, HIV/AIDS, Cystic Fibrosis.
Category III	Progressive conditions where there is no known cure. Treatment is exclusively palliative from the outset. For example, some genetic disorders such as trisomy 13 and 18, inoperable congenital heart disease, inborn errors of metabolism.

Category IV	Conditions that are irreversible but non-progressive and often associated with disability. For example, Cerebral Palsy, Down's syndrome without major heart abnormalities

Source: (ACT 1997)

As illustrated in the Table 2, there are various health conditions that require PC for children and this categorization is essential especially in guiding and identifying children who may have PC needs. In addition, the ACT classification can be used as a "guide for developing care plans and deciding with families the appropriate levels of care and treatment; as well as what to expect over the trajectory of the illness" (Republic of South Africa 2017, p.15).

In high income countries PC is provided based on the above definition, however, in African context, even though policies may be in place, some of the services may take long time to be started. This is because some of these services are not only lacking because of inadequate resources, but some of the services may also require transformation in norms, culture and traditions. Africa has different cultures and traditions which do not apply in western context where the thinking about palliative care originated. In addition, many diseases are diagnosed late as many African people do not undergo regular medical checkups or consult traditional practitioners before going to conventional medical practitioners.

Paediatric palliative care: A global perspective

Whilst the actual need of individuals needing PC is not known, the data provided by the Global Atlas showed that more than 29 million people died from diseases requiring PC, and those who needed end-of-life care were more than 20 million. Of these, only 6% of children needed PC

(World Health Organization 2014). Although these estimates focused more on patients at the end-of-life care and do not cover those with lifelong diseases; understanding the problem in general is important as the statistics are released by various researchers.

More recently, a study that was conducted to estimate the global need for palliative care for children determined that annually more than 21 million children with chronic conditions need PC (Connor et al. 2017). Of these, more than eight million require specialized palliative care, while others require generalized care or a combination of both. The findings further showed that the total need of patients in need of PC in South Africa were 549,778 and those who require specialized care were 207,909. In Kenya, the total needs were 425,014, of those 166,888 needed specialized care, while in Zimbabwe, the total need was 210, 849 and those in need of specialized care are 79,465 (Connor et al. 2017).

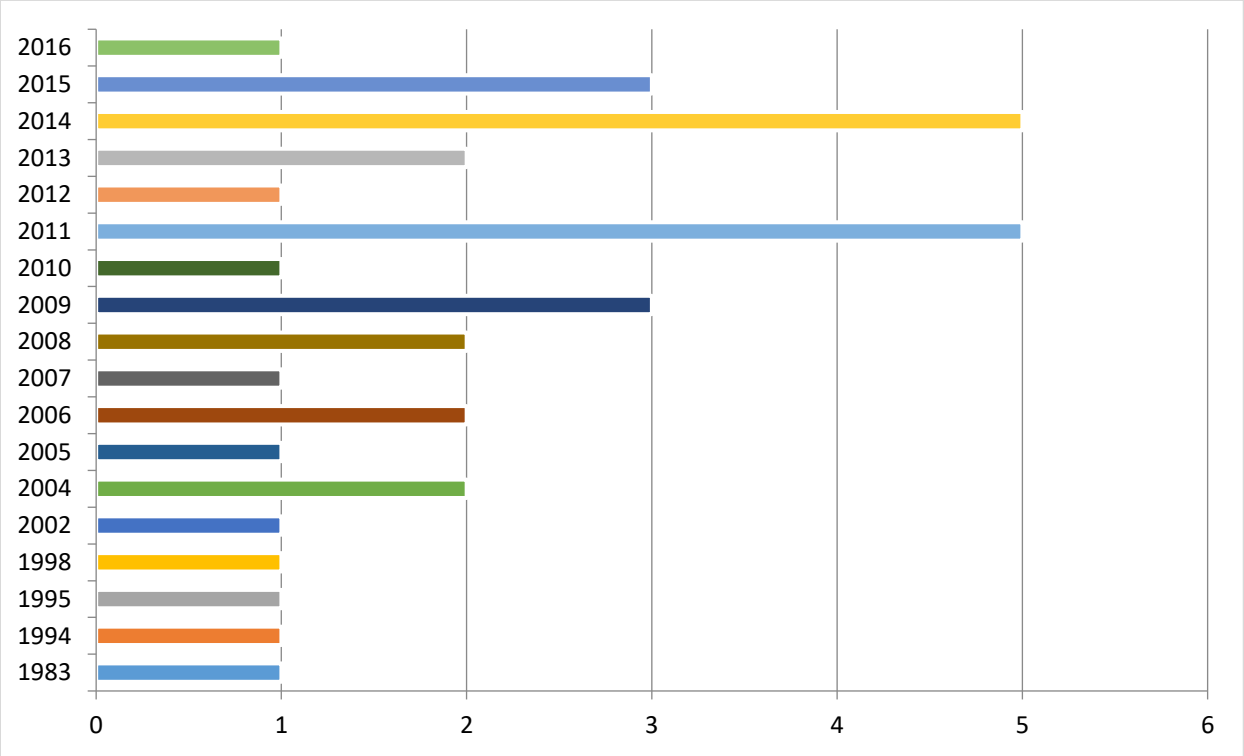
These findings differ significantly from the findings that were published in 2013 that assessed the need for PC for children in South Africa, Kenya, and Zimbabwe (see Connor and Sisimayi 2013). This means that the number of children requiring palliative care in South Africa decreased, while the total number of children requiring palliative care in Kenya and Zimbabwe increased considerably. These discrepancies in data may be due to absence of reliable resources, lack of rigorous data collection and triangulation. Other factors include not knowing which condition to include and exclude, data sources, as well as engagement with clinicians. Whilst the need for PPC is great (Downing et al. 2018), access to PC services remain limited in most parts of the world, particularly in Africa.

Internationally, there have been several initiatives or declarations that promote the development and provision of PPC (see Inbadas et al. 2016) as shown in Figure 1. Some of the initiatives

include the introduction of the International Children's Palliative Care Network (ICPCN). The ICPCN was introduced with the aim of promoting access to PPC and their families through advocacy, education, research, information sharing and networking (Marston et al. 2013). Since children palliative care is less developed than that of adults (World Health Organization 2018), the formation provided by ICPCN offers an opportunity for many countries to learn from each other and improve access to PPC.

Other efforts include the Cape Town Declaration which took place in 2002 which followed by the establishment of the African Palliative Care Association (APCA) in 2004. The declaration emphasized that every adult and child suffering from life-threatening illnesses has the right to access palliative care (Mpanga Sebuyire et al. 2003). The declaration also insisted that PC should be integrated into the national health policies (Mpanga Sebuyire et al. 2003). Since then, many African countries have joined APCA with the aim of improving information, integration, and evidence. Despite these efforts, access to PPC remains inadequate not only in Africa but in most part of the world.

Figure 1: Palliative care declarations since 1983-2016



Source: (Inbadas et al. 2016)

As Figure 1 (above) shows, the number of palliative care declarations started to increase from 1 to 5 declarations from 2011 to 2015. For example, in 2011 and 2014 the number of declarations doubled. The increase in declarations might be because of the high burden of diseases which influenced palliative care associations and international organizations as well as activists to find solutions to overcome the challenges facing the development and access to PC services around the world.

Although there have been more than 34 declarations, only four of them were specific to children's palliative care needs (see Table 3). Some of the declarations include children among the general population while others focus on adult's palliative care needs. However, the extent to which children's PC needs were addressed among these general declarations is not the area of focus in this study.

Table 3: Number of declarations and resolutions that emphasis on PC policy development

No.	**Declaration**	**Year**	**context**	**Key Content/Recommendations**
1.	World Health Assembly (WHA) Resolution 67.19	2014	Global	Emphasis on the member state "*to develop, strengthen, and implement, where appropriate PC policies to integrate PC at all levels of healthcare"*
2	The Prague Charter	2013	Global	Call on government to develop comprehensive health care policies that provide integrated PC
3	Universal Health Coverage (UHC) Resolution	2012	Global	Urge the government to develop and implement evidence-based national policies on PC

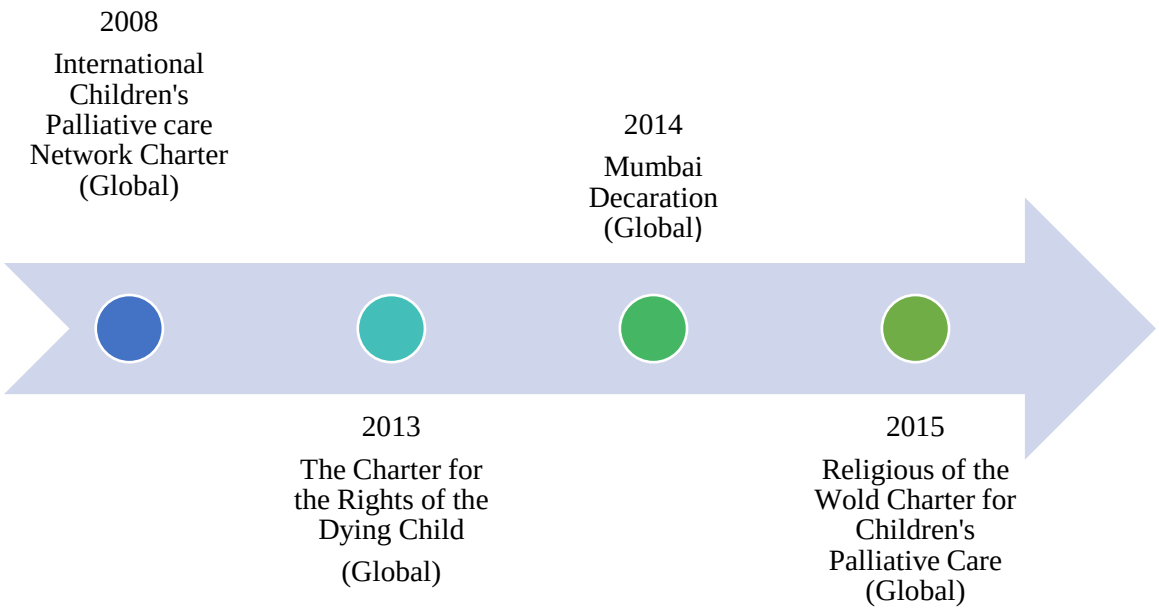
4	WMA Declaration on End-of-life Medical Care	2011	Global	Requests on National medical associations to develop policies on PC and palliative sedation
5	United Nations Political Declaration on Non-Communicable Diseases	2011	Global	Requests for the government to develop and implement national policies on PC
6	The Lisbon Challenge	2011	Global	Calls for the development of health policies to address the needs of patents with life-limiting or terminal illness
7	IAHPC-WPCA Joint Declaration	2009	Global	Urge governments and policy makers to recognize P.C and pain treatment as a human right
8	Korea Declaration on Hospice and P.C	2005	Global	Insists governments to Integrate hospice and P.C in national health policies
9	The Poznan Declaration	1998	Eastern Europe	The declaration emphasizes on the promotion of national policies, education, and drug availability

10	Barcelona Declaration on P.C	1995	Developing countries	Develop clear informed policies

Source: (Inbadas et al. 2016; Luyirika et al. 2016)

As Table 3 above portrays, a significant number of declarations and resolutions emphasize policy development to improve palliative care services. The most recent declarations include the World Health Assembly (WHA) Resolution 67.19 of 2014, the Prague Charter of 2013 and the Universal Health Coverage (UHC) of 2012. They all call on government in all WHO member states to develop and implement PC policies as well as integrating PC at all levels of healthcare (World Health Assembly 2014). According to Luyirika et al (2016) developing a "national PC policy is critical in scaling-up of PC provision that encompasses the relief of pain and other distressing symptoms right from diagnosis, treatment, end-of-life care, and bereavement support for families at all levels of health system" (p. 3). Whilst having national policies on PC is important, how they are implemented at the national level matters most.

Figure 2: Key palliative care declarations that are specific to children



Source: Author's compilation.

As Figure 1 and Figure 2 show even though there have been more than 34 declarations, only four declarations have focused specifically on PPC. Given the increasing demand for PPC in Africa it is obvious that more declarations that focus on children's PC are needed. Although declarations are significant, other efforts to improve PPC needs to be considered as well.

Palliative care as a human right

> *Palliative care for children is an obligatory part of health services…. (They) have the right to receive the necessary physical, social, psychosocial and spiritual care to ensure their development and promote their best possible quality of life*
>
> (Hunt 2007; Pūras, D., 2016)

The concept of right to PC is not new in public health, and it has been described as the ethical responsibility of the health systems (Sharkey et al. 2017). In 2000, the United Nation (UN) Committee on Economics Social and Cultural Rights described PC as a component of children's right to health, however, it only recently started to receive full attention by the UN bodies and states (Ezer et al. 2018; Open Society 2015; Brenan 2007; UN Economic and Social Council 2000). The committee further reiterated in its General Comment 14 that:

> *States are obliged to respect the right to health by inter alia, refraining from denying or limiting equal access for all persons … to preventive, curative and palliative care services.*
>
> (UN Economic and Social Council 2000, p. 12).

Whilst there has been a significant progress in the number of declarations and international laws emphasizing on the right to PPC (Table 4), the development of the right to P.C is mostly seen in older person and as such there is still much to do in the context of the rights to children (Ezer et al. 2018).

Table 4: International laws which recognizes the right to PC

International Human Right Law	**Content**	**Description**
International covenant on Economic, Social and Cultural Rights (ICESCR)	Article 12 (right to health)	These articles (12, 7, 24) state that countries are obliged to take measures to

International Covenant on Civil and Political Rights (ICCPR)	Article 7 (freedom from torture)	ensure that individuals suffering from chronic conditions have access to PC as well as essential medicine for pain control, without forgetting that children are entitled to special care and assistance.
The UN Convention on the rights of the Child (CRC)	Article 24 (child's right to health)	

Source: (Ezer et al. 2018; Open Society 2015; UN economic and Social Cultural Rights 2000)

Again, the right to PC as a human right is not only advocated by the international laws, but also in several palliative care declarations and resolutions as described above. These declarations as well as the international human rights laws are central in advocating for PC for individuals with chronic illnesses, particularly children and that their influence should not be underestimated.

Access to paediatric palliative care in Africa

A literature review indicated that there are few studies in Africa that have examined PPC, however, the researcher found none that has addressed palliative care policies and how they include PPC needs. Despite the increasing need for PC in Africa, evidence has shown that the development of PC is not adequate across the region and limited to a small number of African countries (Rhee et al. 2017; Downing et al. 2015(b)). Although there have been some

developments over the past few years, these developments are more seen in adults' palliative care (Downing et al. 2018; Grant et al. 2011).

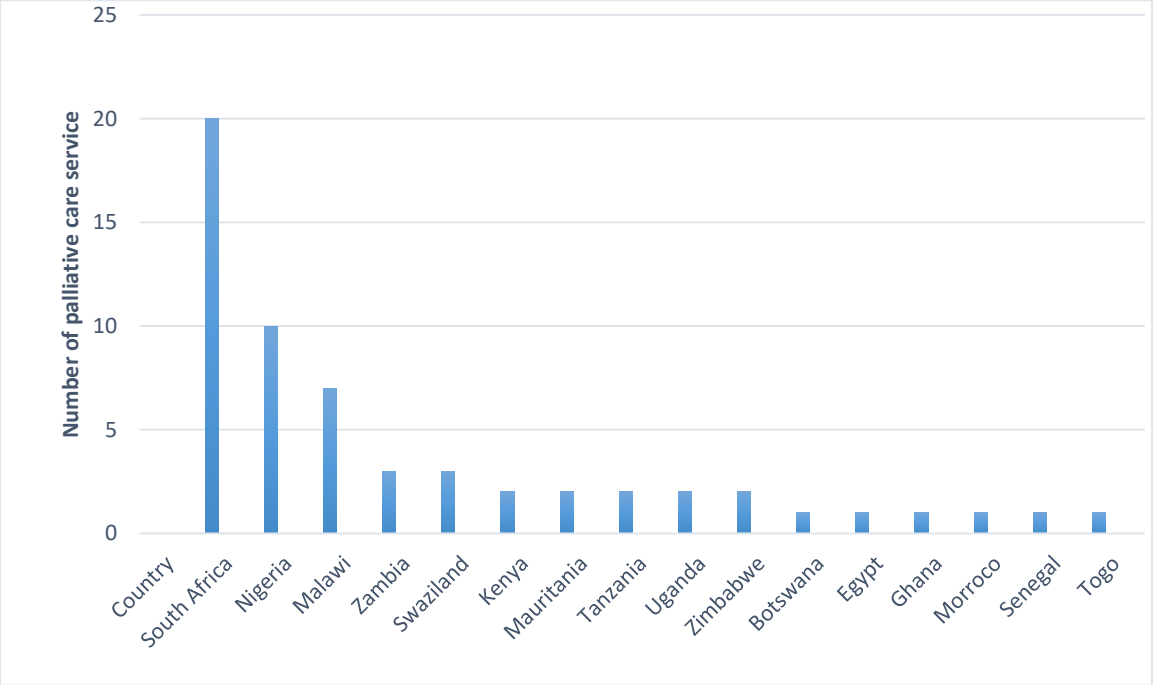
In Africa, PPC is described as a relatively new component of care (Downing et al. 2018). Research shows that the development of PC in Africa was shaped mostly by HIV/AIDS pandemic, particularly in sub-Saharan Africa (SSA) (Knapp et al. 2012, Amery et al. 2009). In 2009, more than 2.3 million children under 15 years of age were living with HIV/AIDS in SSA, with 1.8 million new infections and 1.3 million deaths (United Nations AIDS programme 2012). However, this has changed considerably over the last decade due to the increased use of highly active antiretroviral therapy (HAART) and prevention of mother-to-child transmission (PMTCT) in many African countries (Ngemu et al. 2015). For example, the 2014 report of the United Nations AIDS Programme shows that between 2009 and 2014 there was a 48% reduction of new HIV infections in children around the world (United Nations AIDS Programme 2014; Akinsanya et al. 2017).

However, with the increasing burden of diseases such as non-communicable diseases, the provision of PC services have now extended to include other illnesses including cardiovascular, degenerative neurological diseases, and lung diseases to mention but a few (World Health Organization 2018; Kelly et al. 2015). Although data for cancer in Africa is lacking, available estimates demonstrate that about 166,000 children are diagnosed with cancer annually of which 84% of diagnosis were in developing countries and almost 90% of cancer deaths in developing countries (Downing et al., 2012). However, despite this great need access to PPC in Africa remains limited.

A much more recent study that assessed the state of palliative care development in African countries found that only 19 countries in Africa had information regarding provision of palliative

care (Rhee et al. 2017). However, access to palliative care services differ within African countries, with South Africa, Kenya, and Uganda rated as best countries in terms of PC development and having the greatest number of services as shown in Figure 3 below (Rhee et al. 2018).

Figure 3: Palliative care services across Africa



Source: (Rhee et al. 2018)

As Figure 3 above illustrates, very few African countries have made progress in terms of palliative care development. Uganda, South Africa, and Nigeria are the few countries that have made progress in terms of specialized care development while Botswana, Ethiopia, Rwanda, and Swaziland (now Eswatini) are leading in terms of palliative care policy development (Rhee et al.

2018). Further, African countries which have integrated palliative care into their all health care setting were grouped into different levels (see Table 5).

Table 5: The levels of PC development across Africa

Levels of integration	**Percentage (%)**	**Description**	**African countries**
Group 1	65.5%	These includes Countries with no known palliative care activity	Congo, Somalia, Central Africa republic, Gabon
Group 2	18.8%	Countries with no palliative care services but work in progress to provide services	DR Congo, Burundi, Algeria
Group 3	9.9%	These include countries with isolated provision	Botswana, Angola, Ghana
Group 4a	5.7%	Countries with preliminary integration of PC services into mainstream service provision.	Malawi, Mongolia, Tanzania, SA, Zambia, Kenya, Zimbabwe

Group 4b		Countries with advanced integration into mainstream service provision	Uganda

Source: (Lynch et al. 2013, Knapp et al. 2011)

As Table 5 above illustrates, level one includes countries with no known PC activities while level four include countries that have PC services at an advanced stage of integration into the mainstream health provision (Hannon et al. 2015, Knapp et al. 2012). An important point to note is that most African countries described to have made progress in PC development are the same countries that have also made progress in other PC services such as specialized care, education, and medicine. Some reported barriers that hinder the realization and access to PC services in many African countries include: lack or absence of comprehensive palliative care policies and guidelines; late referrals; myths about PC; limited resources such as access to essential medicines and treatments; funding for PC services; and inadequate trained health personnel (Rhee et al. 2018; Downing et al. 2018; El Ansary et al. 2014; Caruso Brown et al. 2014; Fraiser et al. 2011; Albertyn et al. 2009). Yet, to overcome these barriers, strengthening of health systems in Africa is a must (Knaul et al. 2017).

Alongside health system strengthening, the proposed WHO health systems building blocks framework (Figure 4) is often utilized to assess the systems performance as well as understanding what constitute health systems strengthening (World Health Organization 2007). Assessing the health systems this way is critical to improving access to PC services (Grant et al 2017).

Figure 4: WHO health system building blocks framework

Source: (World Health Organization 2007)

As Figure 4 above demonstrates, the framework provides a useful guide to understanding the important functions of the health systems because challenges facing the development of PC in African countries “requires a more integrated response that recognizes the inter-dependence of each part of the health system” (World Health Organization 2007, p. v). This was shown in studies by Rhee et al (2018) and Lynch et al (2013) when they rank African countries using WHO dimensions, and demonstrate that not a single country has a full package of palliative care services (Table.6). For example, one country may have made progress in terms of education but weak in policy implementation or specialized care.

Table 6: Ranked African countries with PC development

Development of PC	**Specialized care**	**Policies**	**Education**	**Medicine**
South Africa	Uganda	Botswana	Uganda	Swaziland
Uganda	South Africa	Ethiopia	Kenya	South Africa
Kenya	Nigeria	Rwanda	Ghana	Malawi
		Swaziland	Zambia	

Source: (Rhee et al. 2018)

These findings by Rhee et al. (2018) are not different from the findings provided by Lynch et al (2013). The study by Lynch was carried out to map the level of PC development around the world and countries were ranked into four groups (see Table 5). Uganda was the only African country that has reached high level (level four) of PC development. The study further found that 65.6% were at level one; 18.8% countries at level two; 9.9% countries were at level three and only 5.7% were at level four (Lynch et al. 2013).

Whilst access to PPC remains low, different models for PC exist in Africa that address different levels of PC needs such as generalist, intermediate or specialist care or in combination. Table 7 below shows examples of models of delivering PC that exist in Africa. These include hospital-based PC, specialist care, and home-based PC.

Table 7: Models of palliative care in Africa

No.	Model	Description
1	Hospital-based palliative care	Provision of palliative care services is within a hospital context and can offer generalist, intermediate or specialist care. Palliative care services may include both inpatient and outpatient services.
2	Specialist care	May be provided across all levels of care which include tertiary, secondary and primary. This model is fundamental because it addresses complex needs of patients and their families with conditions requiring PC as well as providing leadership, training, mentorship, and supervision.
3	Home-based palliative care (most used model in Africa)	This may involve a combination of PC health care providers that visit and support patients directly in their homes. This may also include generalist or intermediate care delivered through home-based care, services provided by community-based programmes, and trained volunteers.
4	Outreach services	Some PC providers in Africa have outreach services that support other organizations to provide PC or provide roadside services and mobile clinics.

Source: (Sasaki et al. 2017; Mwangi-Powell and Dix 2011; Downing et al. 2010)

As Table 7 shows, whilst different models of PC exist in Africa, the most used model is home-based palliative care, and this is because of inadequate resources (Downing et al. 2010; Mwangi-Powell et al. 2013; Harding et al. 2014). Home-based palliative care model aims to facilitate healthcare broader coverage and is described as central in reaching the most vulnerable families (Naicker et al. 2016). In PC settings, a family is considered as the unit of care with support from community based programmes and trained volunteers playing a central role in providing a continuum of holistic care to children requiring such care (Mabude et al. 2008).

Conclusion

The increasing burden of communicable and non-communicable diseases, particularly in Africa has created an urgent need to provide and develop PPC services. This literature review has shown that studies regarding PPC in Africa are not widely available. It established that even in countries where palliative care policies are in place much attention has been given to adults, leaving children behind. This is because care for children requires special attention and multidisciplinary teams that understands the needs of children requiring PC services. Indeed, as this literature review shows there is a huge need for PPC care in Africa and disparities between countries that provide PPC services. Although there has been an ongoing advocacy pertaining to the need for PPC, including human rights, African countries still face some challenges in the provision and development of PPC. Therefore, for African countries to make strides on provision of PPC, training for the health care providers is necessary. Also, advocacy and creation of awareness of PC to the community can streamline the provision and access to the services. However, all these may be achieved, if there are specific policies and or specific policy statements and provisions for PPC are in place.

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Appendixes

Appendix 1: List of databases searched

List of databases searched, key terms and strategies (Literature Review)

PUBMED (780)	**PsyCINFO (via EBSCOhost) (530)**
Palliative OR end-of-life OR hospice OR respite care OR care of dying OR life-limiting OR life-threatening OR progressive conditions OR neurodegenerative OR degenerative OR spinal cord diseases)) AND (pediatric OR paediatric OR child OR children)) AND (Policy OR policies) AND (Africa OR African OR Algeria OR Angola OR Benin OR Botswana OR “Burkina Faso” OR Burundi OR Cameroon OR “Canary Islands” OR “Cape Verde” OR “Central African Republic” OR Chad OR Comoros OR	“(“Palliative" OR "end-of-life" OR "hospice" OR "respite care" OR "care of dying" OR "life-limiting" OR "life-threatening" OR "progressive conditions" OR "neurodegenerative" OR "degenerative" OR "spinal cord diseases”) AND (“pediatric" OR "paediatric" OR "child" OR "children”) AND (“Policy" OR "policies") AND (Africa OR African OR Algeria OR Angola OR Benin OR Botswana OR “Burkina Faso” OR

Congo OR “Democratic Republic of Congo” OR Djibouti OR Egypt OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR “Ivory Coast” OR “Cote d'Ivoire” OR Jamahiriya OR Kenya OR Lesotho OR Liberia OR Libya OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mayotte OR Morocco OR Mozambique OR Namibia OR Niger OR Nigeria OR Principe OR Reunion OR Rwanda OR Sao Tome OR Senegal OR Seychelles OR “Sierra Leone” OR Somalia OR “St Helena” OR Sudan OR Swaziland OR Tanzania OR Togo OR Tunisia OR Uganda OR “Western Sahara” OR Zaire OR Zambia OR Zimbabwe)	Burundi OR Cameroon OR “Canary Islands” OR “Cape Verde” OR “Central African Republic” OR Chad OR Comoros OR Congo OR “Democratic Republic of Congo” OR Djibouti OR Egypt OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR “Ivory Coast” OR “Cote d'Ivoire” OR Jamahiriya OR Kenya OR Lesotho OR Liberia OR Libya OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mayotte OR Morocco OR Mozambique OR Namibia OR Niger OR Nigeria OR Principe OR Reunion OR Rwanda OR Sao Tome OR Senegal OR Seychelles OR “Sierra Leone” OR Somalia OR “St Helena” OR Sudan OR Swaziland OR Tanzania OR Togo OR Tunisia OR Uganda OR “Western Sahara” OR Zaire OR Zambia OR Zimbabwe)
Google Scholar (212)	Palliative OR end-of-life OR hospice OR respite care OR care of dying OR life-limiting OR life-threatening OR progressive conditions OR neurodegenerative OR degenerative OR spinal cord diseases AND Africa
Total articles included in the literature review	24

Appendix 2: List of databases searched for policy documents and key terms

MoH/MoHSW,WHO, UNICEF, USAID,APCA, ICPCN, Google (14), Personal contact (3)	Palliative care, hospice, end-of-life, respite care, and care of dying Paediatric palliative care, pediatric, child, children and health policy, non-communicable diseases, long-term health conditions and Africa
Total policy document included in the study	10

Appendix 3: Summary of the retrieved articles for literature review

Author (s) and year of publication	*Study tittle*	*Country*	*Study aims*	*Study methods*	*Findings*
Amery JM et al. 2009	The beginning of children's palliative care in Africa: Evaluation of a children's palliative care services in Africa	Africa	To evaluate children's palliative care services designed specifically for a resource poor Sub-Saharan African setting	Mixed methods	There is an increase in referrals as well as proportion of children on program, and improved prescriptions of essential medicines such as morphine and chemotherapy
Albertyn R et al. 2009	Challenges associated with paediatric pain management in Sub-Saharan Africa	Sub-Saharan Africa	To review barriers that prevent sick and injured children from accessing basic pain care	Review	There are many factors that hinder/prevent most children from accessing pain management drugs such as inadequate training, language barriers, cultural diversity, limited resources, and high burden of diseases.

Caruso Brown et al. 2014	Reported availability and gaps of pediatric palliative care in low-and-middle income countries: a systematic review of published data	LMICs	To describe palliative care services available to young people with life-limiting conditions and assess core elements with respect to availability, gaps, and under-reported aspects.	Review	Most gaps are recorded in national health systems, specialized education, and access to pain management drugs such as opioids.
Connor S. R and Sisimayi C. 2013	Assessment of the need of palliative care for children: Three country report: South Africa, Kenya and Zimbabwe	South Africa, Kenya, and Zimbabwe	To estimate the need for CPC gaps at the country level	Cross-sectional	The reviewed countries showed an increased number of children requiring generalized PC as well as specialized care.

Connor et al. 2017	Estimating the global need for palliative care for children: a cross-sectional analysis.	Global	To create an accurate global estimate of the worldwide need for children palliative care.	Cross-sectional design	The need for PPC is high particularly in African countries
Downing et al. 2015(a)	Children's palliative care in low-and middle-income countries	LMICs	To review the status of children's palliative care services in LMICs.	Review	Although there has been a progress in adults PC, less attention has been devoted to CPC.
Downing et al 2015(b)	Priorities for global research into children's palliative care: Results of an international Delphi study	Global	To identify and prioritize research areas in children's palliative care	Mixed method	The top priorities were recorded in five areas which are: children's understanding of death and dying, pain management in children, funding, training, and WHO two-step analgesic ladder for pain management in children

Downing et al. 2018	Paediatric palliative care in resource poor-countries	LMICs	To explore the need for PPC globally and particularly in LMICs.	Review	High-quality PPC service provision can be provided in resource-poor settings
Ezer et al. 2018	Legal support for palliative care patients	Global	To trace the origins of legal support for PC patients, detail models of legal support and describe achievements and challenges	Review	Legal issues that were mostly common includes disposing of property and drafting wills, planning for children, dealing with debt as well as securing social benefits and addressing discrimination
Fraser et al. 2017	Palliative care development in Africa: lessons	Uganda, Kenya	To examine the impact of approaches to palliative care in Uganda and Kenya in five domains of education and	Review	In all studied domains, all countries have implemented strategies to develop palliative care

	from Uganda and Kenya		training, access to opioids, public and professional attitudes, integration into national health systems and research		
Grant et al. 2017	Integrating palliative care into national health systems in Africa: a multi-country intervention study	Kenya, Rwanda, Uganda, Zambia	To assess the integration of PC into national health systems in Africa	Mixed methods	Integration of palliative care into national health system was in different ways which include rapid integration which tended to occur where there is pre-existing exposure to PC whereby the national level hospitals are recorded to be slower to attain integration due to their size and complexity
Hannon et al. 2016	Provision of palliative care in low- and middle-income countries:	LMIC	To assess approaches to improve the delivery of effective palliative care in	Review	Fulfilling the humane and legal responsibility of making PC universally available will require the implementation of public health approach

	overcoming obstacles for effective treatment delivery		LMICs for patients with advanced cancer		
Harding et al. 2014	Pediatric palliative care in Sub-Saharan Africa: A systematic review of the evidence for care models, interventions, and outcomes	Africa	To systematically review the evidence for pediatric palliative care models, interventions, and outcomes to appraise the state of the science and inform best practice	Review	Despite the increasing need of pediatric palliative care in sub-Saharan Africa, very little evidence for models, interventions, or outcomes exists.
Inbadas et al. 2016	Palliative care declarations: mapping a new	Global	To explore PC declarations to map new form of interventions	Letter	There was an increase of palliative care declarations in a five-year period 2011 to 2015

	form of intervention				
Knapp et al. 2011	Pediatric palliative care provision around the world: a systematic review	Global	To explore paediatric palliative care provision around the world	Review	Most countries around the world had no known palliative care activities and very few had provision reaching mainstream providers.
Luyirka et al. 2016	Best practices in developing a national palliative care policy in resource limited settings: lesson from five African countries	Africa	To share experiences about best practices when advocating the national palliative care policies	Review	There is a need for countries to assess the need of palliative care prior developing a policy to identify key gaps that need to be covered and addressed by policy implementation

Lynch et al. 2012	Mapping levels of palliative care development: a global update	Global	To categorize PC development around the world	Multi-method approach	Most of the world's countries have made progress in the provision of palliative care services including Africa.
Mwangi-Powell et al. 2013	Models of delivering palliative care and end-of-life care in sub-Saharan Africa: a narrative review of the evidence	Sub-Saharan Africa	To examine the evidence for models of PC and end-of-life care delivery in sub-Saharan Africa since 2010	Review	There is an increase in PC and end-of-life care service development, due to increased advocacy. However, PC services heavily rely on NGOs, community-based and home-based care models
Rhee et al. 2017	Palliative care in Africa: a scoping review from 2005-16	Africa	To assess PC development in African countries	Review	PC services are mostly concentrated in few African countries (Kenya, South Africa, and Uganda

Rhee et al. 2018	Factors affecting palliative care development in Africa: in-country expert' perceptions in seven countries	Africa	To identify key factors affecting PC development in African countries	Mixed methods	Advocacy was the key factor that facilitated the development of PC in Africa
Sasaki et al. 2017	A scoping review of palliative care for children in low-and-middle income countries	LMICs	To identify and summarize the current needs, accessibility, quality, and models of palliative care for children in LMICS	Review	There is an urgent need for palliative care, especially in training for health workers and improving poor availability and/or accessibility to PC including medication and bereavement.

Part C: JOURNAL SUBMISSION

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Analysis of Palliative Care Policies in Africa: Implications for Paediatric Palliative Care

Targeted: *Journal of Health Policy and Planning (HPP)*[3]

Epiphania Ngowi[4]

Abstract

It is widely acknowledged that provision of paediatric palliative care remains a global public health challenge. This study explores paediatric palliative care policies in Africa. It does this through a documentary review of existing palliative care policies to examine the extent to which these documents exist and cater for children's needs. The study found no paediatric-only palliative care policies, and it, therefore, considered policies for adult palliative care and non-communicable diseases (NCDs), and explored whether these policies catered for children. The review established that out of 54 African countries, only eight countries had policy documents that met the inclusion criteria. Out of these, five were palliative care and five were NCD policies. None were specific or exclusive to paediatric palliative care but addressed or had implications for paediatric palliative care to various degrees. The analysis of these policy documents established that paediatric palliative care needs are not adequately addressed in existing general palliative

[3] Author's instruction guide is in Appendix 2

[4]For the manuscript, the principal investigator is the sole and first author of this study.

care policies in Africa. This article argues that lack of specific and comprehensive paediatric palliative care policies in Africa call for urgent intervention from all stakeholders in the health sector. In the absence of specific policy to address an issue such as paediatric palliative care, there will be no meaningful plans or budgetary allocations to address the challenge.

Key terms: *Palliative care, paediatric palliative care, policy, non-communicable diseases, Africa*

Key messages

- Few palliative care polices exist across Africa that include and address children palliative care needs. Instead, most policies focus on adults. This leads to inadequate and inequitable access to paediatric palliative care services.
- While paediatric palliative care is mentioned in several African countries' palliative care policies, it is not adequately addressed in a way that caters for children's palliative care needs.
- Despite having a similar underlying philosophy to that of adult palliative care, children have unique needs that require special paediatric palliative care.
- Most health systems in Africa do not have formal structures or mechanisms that bring individuals together within a multidisciplinary approach – a key requirement to ensure meaningful provision of paediatric palliative care.
- The formulation processes for most palliative care policies in Africa were donor funded, and due to limited domestic resources, implementation and monitoring of these policies continues to be influenced and shaped by donors.

Introduction

The World Health Organization (WHO) and governments around the globe agree that the provision of paediatric palliative care (PPC) is crucial, because it improves the quality of life of children suffering from life-threatening and life-limiting illnesses (Downing et al. 2016; World Health 0rganization 2014). Despite this global recognition, access to PPC remains limited, particularly in Africa (Connor et al. 2017). Currently, there are only a handful of studies on palliative care in Africa and these tend to focus on adult PC. This study seeks to contribute knowledge on palliative care (PC) in Africa, by identifying PC policies and examining the extent to which such policies address PPC needs.

PC can improve patients' and their families' quality of life when they face a life-threatening or life-limiting illness (Thaniyath et al. 2019). In general, PC involves preventing and easing pain when administered early and proper assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization 2002).

Having clear policy on PC is important, as it increases the potential for the formulation of clear implementation plans and obtaining budgetary allocations to deliver PC (Rajan et al. 2016). Furthermore, policy influences service requirement, development, and availability of care that a child and their family would have access to[5]. The provision of PPC, such as health care

[5]The Social Ecological Model, a framework for disease prevention shows that policy is central in guiding the provision of health services. The model consists of five levels: policy/enabling environments (national, state, local laws), organizational (organizations and social institutions), community (relationships between organizations), interpersonal

professional's consultation with children and families, not only increases family satisfaction with care, but enables families to better manage distressing symptoms, and improve their communication and coordination with service providers (Kang et al. 2016; Voyles 2013; Geer et al. 2012).

In Africa, attention to PC escalated significantly in response to the growing burden of the HIV/AIDS (Uys 2003). For example, in the early 1990s, South Africa started providing critical PC services to infants, children and adults dying of HIV (Republic of South Africa 2017). However, with the increasing burden of diseases such as non-communicable diseases (NCDs), in most African countries, PC services are extended to cover other diseases including cardiovascular, degenerative neurological diseases, and lung diseases, amongst others (Abraham et al. 2002).

Despite the increasing need for PC, very few countries in Africa have palliative care policies. In 2016, there were six African countries with PC policies (Swaziland, Mozambique, Rwanda, Malawi, Zimbabwe, Tanzania), while Uganda and Botswana were drafting their national policies (Downing et al. 2016). This is not surprising, however, considering that PC is still in its infancy in Africa (Harding et al. 2014; Dix 2012).

(families, friends, social networks), and Individuals (knowledge, attitudes, behavior).

http://www.cdc.gov/violenceprevention/overview/social-ecologicalmodel.html

Since this review is based on PPC, it is important to consider its differences with adult PC. PPC is defined as the “active total care of the child’s body, mind and spirit, and includes giving support to the family” (World Health Organization 2002). PPC starts when an illness is diagnosed and continues regardless of whether or not a child receives treatment for the disease (World Health Organization 2002). Although aspects of PPC are like that of adult PC, in practice the provision of care to children is quite different (Wolfe et al. 2000). Palliative care for children must consider age, the underlying illness, and their perception of their illness and dying, which are significantly influenced by their developmental age (Lück 2014; Marston and Chambers 2012). According to Novak et al (2012) most children suffering from life-threatening or life-limiting illnesses face intellectual and development disabilities and may need help to express themselves. It is for these reasons that Marston and Chambers (2012) have argued that children in need of palliative care have diverse and complex diseases that require special attention. Yet, despite these diverse needs, access to PPC remains a challenge worldwide.

It is important to note that PC should not be considered as an “alternative” method of care, but rather, a method of care that co-exists with curative treatments to provide children and families with the best possible comprehensive treatment of life-limiting or life-threatening illness (Crozier and Hancock 2012, p. 199).

Unlike developed countries, in Africa access to PC services is even more challenging and in some countries this service is non-existent (Downing et al. 2017). Barriers that hinder the development and access to PPC services are multifactorial. Some factors include lack of funding, high burden of diseases, PPC not prioritized, PC not integrated into the main healthcare services; lack of PC training for health care professionals and a general lack of human resources; poor referrals to

PC; and inadequate essential medicines to mention but a few (Downing et al. 2018; Rhee et al. 2018). These are all underpinned by the absence of policies and guidelines (Downing et al. 2018; Davies et al. 2008). Evidence shows that although some countries may have policies on HIV or non-communicable diseases (NCDs), these may or may not include the required provisions for PPC (Downing et al. 2018).

To address the above challenges, the World Health Organization (WHO) has frequently called for governments to use a public health approach to increase access to PC services[6] (Downing et al. 2016). As Figure 1 below shows, the WHO recommended approach encompasses four pillars, which include appropriate policies, adequate drug availability, education of health workers and implementation.

[6]The public health approach includes integrating palliative care into all levels of health care systems (Stjernsward et al. 2007), as well as revising laws and procedures to facilitate access to relief and pain medicines, and training health workers in palliative care (World Health Organization 2014).

Figure 1: Public Health Approach

Source: (Stjernsward et al. 2007)

In this approach, the fundamental part is the presence of a policy which provides for and guides the implementation of various interventions such as the provision of essential medicines, education and training of the health care providers as well as funding for PC services. This approach offers more options and cost-effective interventions which suit different contexts and, hence, are more likely to receive buy-in from both government and civil society (Stjernsward et al. 2007). More recently, the World Health Assembly (WHA) called for governments to adopt WHA Resolution 67.19, which promotes the “development, strengthening and implementation of PC

policies to support the comprehensive strengthening of health systems, to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels of care" (World Health Assembly 2014, p. 39; World Health Organization 2018). Yet, despite these frequent calls, access to PPC remains a challenge in many countries.

The Global Atlas on PC estimated that 7 million children need PC at the end of life; of these, 49% live in Africa (Connor and Sepulveda 2014). However, this estimate focuses more on end-of-life care and does not include children with life-threatening and life-limiting illness, who need PC earlier. It therefore underestimates the actual need (Connor et al. 2017; Connor and Sepulveda 2014). As Waldman and Wolfe (2013 p. 55) put it, palliative care "is not simply about dying, but rather about how to achieve the highest quality of living while facing potentially life-threatening and life-limiting illness". Also, statistics provided by the Global Atlas of Palliative Care at the End of Life do not cover those patients who fall under the World Health Organization (WHO) definition, which requires provision of PC the moment a person is diagnosed by life-threatening condition. However, since the statistics estimating the need for PC for both adults and children are normally based on mortality (Connor et al. 2017), the true numbers of children needing PC is not known.

Using this expanded definition, a recent assessment of the global need for PC for children estimates that 21 million children need PC (Connor et al. 2017). This figure is three times the Global Atlas estimate provided in 2014. Of these, more than 8 million require specialized PC, while others will require generalized care or a combination of both (Connor et al. 2017). The need for PC is high in low-resourced settings and particularly in countries with high rates of HIV/AIDS and non-communicable diseases (NCDs) (Downing et al. 2018), as well as those in Sub-Saharan Africa (Rhee et al. 2017; Connor and Sisimayi 2013; Knapp et al. 2011). To advocate for children's

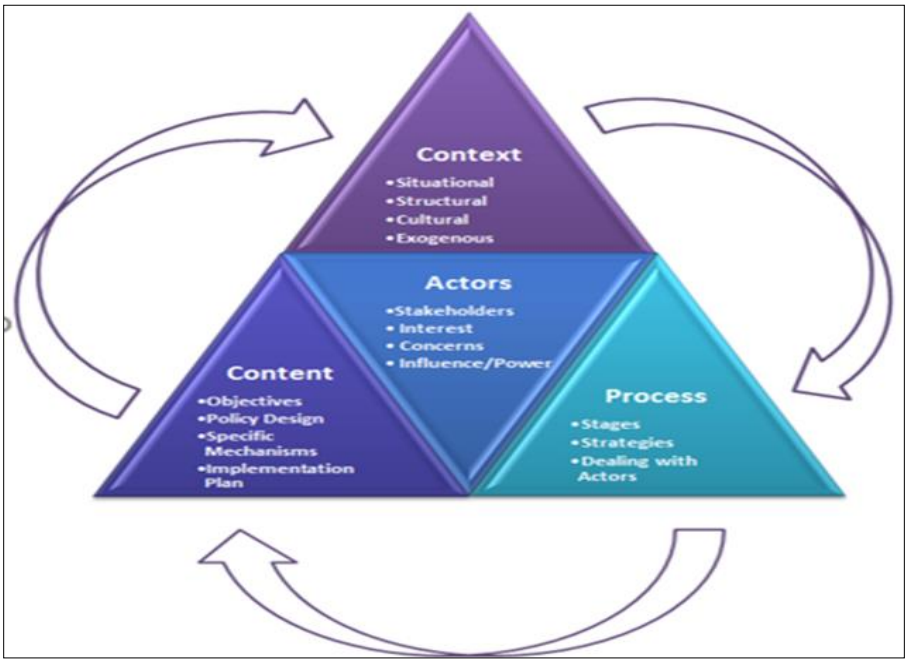
PC needs, it is important to know what policies exist and whether such policies address the needs of children adequately.

It is on these bases that this policy review explores the existing palliative care policies in Africa and examines the extent to which such policies address children's needs. Within the African context, this review is considered critical because there is no study that has thoroughly investigated PPC policies in the continent. By documenting what policies exist and assessing the extent to which such policies address children's needs, this study fills the literature gap on PPC in Africa and contributes to the growing body of literature on PPC in general. Further, the study contributes important lessons that can aid policy makers with the design of specific policies to guide children's palliative care in Africa.

Analytical framework

The analysis drew on Walt and Gilson's (1994) policy triangle framework. As Ostrom (2007) argues, the use of a framework in analysing policies enables researchers to identify policy elements as well as the relationships between them. The framework highlights ways of understanding the aspects and forces that influence why and how policies are initiated, formulated, negotiated, communicated, implemented and evaluated and incorporates the four components of context, content, process, and actors (Figure 2).

Figure 2: Policy analysis triangle



Source: (Walt and Gilson 1994).

The context of the policy refers to the systemic factors which include political, social, economic, and the international environment (Letcher 1979; Buse et al. 2005), while the content of the policy refers to the goals or objectives of the policy, policy design, and the implementation plan. Policy process relates to the set of decisions as well as non-decisions made by interest groups such as policy actors. Policy actors are the individual groups and organizations involved in the policy (Buse et al. 2005). According to Gilson et al (2008), policy actors are the 'heartbeat' of the policy and the policy process, because of the influence they have on policy development. This review applied the policy triangle framework, not only because it is the most used framework in LMIC policy analyses (Gilson and Raphael 2008), but because it is appropriate to address the objectives of the study.

This study did not look at all four components of the triangle to the same level of detail. The analysis gave greater weight to the policy content, to ascertain what exactly policies proposed with respect to PPC.

Although this study mainly focuses on the content of the policy, it also briefly analyses process, contextual factors that led to the formulation of the policy, and key actors involved in policy formulation.

Methods

This study was conducted from April 2017 to September 2019. The study was done by the principal investigator through a desk-based review, with regular review and discussion with supervisors.

Study design

This is a documentary review of existing palliative care policies in Africa. Documentary review is hailed as an efficient method, especially during data analysis, because it does not require time and resources devoted for producing primary data through surveys or experimental methods (Bowen 2009). In addition, a documentary review provides an opportunity to triangulate extracted information and may come up with issues that would have otherwise not been observed through other methods of data collection such as surveys (Centers for Disease Control 2009).

Document selection

Inclusion and exclusion criteria

Documents included palliative care policies, whether targeted at adults, children or both. Secondly, it included policies on non-communicable diseases (NCDs), as well as policies on long-term health conditions (LTHCs) or chronic diseases, on the premise that these may contain aspects of palliative care. The study was limited to Africa and included documents published between 2002 till 2019.This period was chosen to capture all policies that were developed after the Cape Town Declaration on Palliative Care in 2002.

HIV policies that were not relevant to children were excluded. The study did not include guidelines as it focused only on official policy documents. Only policies published in English were included and we accept the limitation of possibly missing out on policies from Francophone and Lusophone countries in Africa.

Data Collection

The study hand-searched government and palliative care-related organizational websites, as conventional search engines do not contain such policy documents. Relevant reports and other policy documents were explored on websites from the Ministry of Health and Social Welfare (MOH/MOHSW), departments of health and international agencies such as the World Health Organization (WHO), United Nations International Children's Emergency Fund (UNICEF), and United States Agency for International Development (USAID), Alliance for Health Policy and Systems Research, African Palliative Care Association (APCA), and the International Children's

Palliative Care Network (ICPCN). A further google search was performed to look for other government or non-government related literature on the subject in question. The search was performed using the following key terms: ‘palliative care’ ‘hospice’, ‘end-of-life’, ‘respite care’ and ‘care of dying’; ‘paediatric palliative care’, ‘paediatric’, ‘pediatric’, ‘child’, ‘children’; ‘health policy’, ‘non-communicable diseases’, ‘long-term health conditions’ combined with ‘Africa’. In addition, the third author who is an expert in the paediatric palliative care field obtained the rest of the policy documents that we could not secure through normal desk-based searches, via email communication with her peers who work in the field of PPC in their respective countries.

Data extraction and analysis

Data from the policy documents were extracted into Microsoft excel. Since the study follows the structure of a systematic review, themes and sub-themes were identified prior to in-depth analysis. Four overarching themes are those from Walt and Gilson (1994) conceptual framework of policy analysis. These include content, context, process, and actors. Twelve subthemes were coded for under the content theme, based on successful palliative care policies from High Income Countries (HIC), which are Ireland, United Kingdom and Australia. The selected subthemes are: (1) targeting of children (2) adherence to WHO definition of PPC and guidelines (3) PC objectives (4) pathways to care (5) child-and family-centredness (6) multidisciplinary teams (7) education programmes (8) health work force (9) strategies to support health care providers (10) budgeting (11) monitoring and evaluation and (12) implementation plans. These subthemes guided the analysis of the specific content proposals of the policy documents.

The sub-themes were retrieved from these policies because these are key requirements for a meaningful provision of PPC services, and that a good policy should contain all these aspects. Further, the selected countries have made progress in the development and provision of PPC services. For example, the United Kingdom have been praised for providing several key documents that are instrumental to PPC needs. A key document is the recommendations for care of children with life-threatening and life-limiting conditions as well as the classification of conditions requiring palliative care for children which was developed by the Association for Children with Life-threatening or Terminal Conditions and their families (ACT) in 1997.Therefore, drawing lessons from their policy documents enabled us to understand the elements of best practices and the contents of PPC.

Moreover, four aspects of macro-context, politics, finances, and human resources were coded for as well as the micro-context of policy implementation. In relation to process, information on how the policy process unfolded as well as whether they drew on evidence was included. The analysis explored the actors involved in the policy development process, as well as for those for whom the policy has implications. In line with this, actors were classified according to different levels of operation: political, service delivery and community level.

Ethics considerations

There was no ethics approval required for this review since it involves publicly available policy documents. However, the review proposal was submitted to the University of Cape Town, Faculty of Health Science Dissertations Approval Committee for approval before proceeding with the research.

Results: Existence and non-existence of PC policies in Africa

In total, 17 policy documents were identified through government websites, international agencies and through personal contact. Only ten (n=10) policy documents were eligible for inclusion in the review. The other 7 policies were excluded because they were not from Africa while others were not PC or NCD policies. Five (n=5) of the included documents were stand-alone palliative care policies and five (n=5) were non-communicable diseases (NCDs) policies. The initial search identified seven (n=7) documents and the other three (n=3) documents were obtained through personal contacts. The policy documents were retrieved from eight countries including South Africa, Rwanda, Malawi, Zimbabwe, Ghana, Nigeria, Swaziland, and Egypt (Table 1).

Table 1: Summary of the policy documents identified and analysed

Country	Title of the document	Year	Targeted population	Actors
Rwanda	Rwanda National Palliative Care Policy	2011	Adults and children	Government officials from the ministry of health, led by the Minister for Health and representatives from NGO'S.
Swaziland (Eswatini)	National Palliative Care Policy	2011	General population	Government officials from the ministry of health

Ghana	National Policy for Prevention and Control of Non-Communicable Diseases in Ghana	2012	Adults and children	Government officials from the ministry of health
Nigeria	National Policy and Strategic Plan of Action on Non-Communicable Diseases (NCDs)	2013	Adults and children	Government officials from the ministry of health, led by the Minister for Health and representatives from NGO'S.
Malawi	Malawi National Palliative Care Policy	2014	Adults and children	Government officials from the ministry of health
Zimbabwe	The National Palliative Care Policy	2014	Adults and children	Government officials from the ministry of health, led by the Minister for Health and representatives from NGO'S.
Rwanda	Non-communicable Disease Policy	2015	General population	Government officials from the ministry of health
Swaziland	National Non-communicable	2016	Adults	Government officials from the ministry of health

	Disease Prevention and Control Policy			
South Africa	National Policy Framework and Strategy on Palliative care (NPFSPC) 2017-2022	2017	Adults and children	Government officials from the ministry of health, led by the Minister for Health and representatives from NGO'S.
Egypt	National Multi-sectoral Action Plan for Prevention and Control of Non-communicable Diseases 2017-2021 (EgyptMAP-NCD)	2017	General population	Government officials from the ministry of health, led by the Minister for Health and representatives from NGO'S.

As Table 1 shows, the retrieved policies were published over a 7-year period with the earliest released in 2011 (Republic of Rwanda, Kingdom of Swaziland (now Eswatini) and the most recent in 2017 (being policies for Republic of South Africa and Republic of Egypt). Our search from online sources shows that other African countries that have PC policies include Botswana, Mozambique, and Uganda. However, we were unable to access policy documents from the above countries because these documents were not available online, and our struggle to reach out to country experts or other allies did not materialize.

The analysis also shows that none of the countries has an exclusive PPC policy, but three countries (South Africa, Zimbabwe and Malawi) have substantial statements and provisions for PPC in their adult PC policies and also in the NCD or LTHC policies that relate to children's PC. The other four countries of Ghana, Rwanda, Egypt, and Nigeria have some reference to PPC and the remaining country (Swaziland) does not have direct statements on children's palliative care needs.

Amongst the ten reviewed policies, we found five PC policies follow the WHO guidelines on the provision of PC and WHA resolution that require countries to offer comprehensive PC to all people in need. These are policies for South Africa, Zimbabwe, Malawi, Rwanda, and Swaziland. For example, the Swaziland policy states: "All people with life-limiting illnesses will access quality palliative care services delivered in a timely, affordable and appropriate manner" (Kingdom of Swaziland 2011, p. 18).

Likewise, the Rwandan policy states:

> *All people-including children-living in Rwanda with a progressive life-limiting illness, their families and caregivers will have access to a health system that provides high quality palliative care services that are well coordinated, innovative and responsive to their needs in affordable and culturally appropriate manner by 2020 (Republic of Rwanda 2011, p. 1).*

Among the ten policies reviewed, the most recent policy – the Framework and Strategy for Palliative Care in South Africa (Republic of South Africa 2017) is the most detailed and comprehensive on PC in general and on PPC. A substantial section is devoted to PPC explaining

in detail how children's palliative care services should be provided to meet the needs of children requiring such care and allocation of budgetary and human resources (Republic of South Africa 2017).

Contextual factors that led to the development of PC policies

Adoption of international resolutions

The analysis of both PC and NCDs policy documents reveals that different contextual factors facilitated the development of the ten policies. In our analysis, the policy documents show that the adoption of the WHA Resolution 69.17 of 2014, and the WHO Global Action Plan for NCDs 2013-2020 facilitated the development of the country-level policies (Republic of South Africa 2017; Republic of Egypt 2017; Republic of Swaziland 2016). For example, in South Africa, (which also co-sponsored the resolution) developed its National Policy Framework and Strategy for Palliative Care (NPFSPC) based on WHA resolution, which calls all its member states to "develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes" (World Health Organization 2018 p. 76; World Health Assembly 2014). The resolution further refers specifically to children as a group requiring special attention and requests collaboration with UNICEF and other relevant partners to promote and implement PPC (World Health Assembly 2014). In its message to the Steering Committee on PC, the NPFSPC states:

> *We are aware that the WHA Resolution could simply remain that; just a Resolution which fails to touch the lives of people … in South Africa, we have accepted the obligation to translate the Resolution into action (Republic of South Africa 2017 p. 4).*

Likewise, the NCD policy in Ghana was also inspired from the existing national and international resolutions, policies and strategies including WHA resolutions from 1998 -2008, and WHO Action plans for the Prevention and Control of NCDs 2008 -2013.

Support from the International agencies

Policy documents revealed that the involvement of the international agencies such as the WHO, USAID, Mildmay International, IntraHealth International, the United States Agency for International Development (USAID) and the US President's Emergency Plan for AIDS Relief (PEPFAR) played an important role in the development of the policies. The above organizations provided technical and financial support to almost all the studied countries. For example, in Rwanda, financial support was provided by PEPFAR, while IntraHealth International and Mildmay International provided technical support, advice, and leadership throughout the entire policy development process (Republic of Rwanda, 2011). Other countries which received technical and financial support were Malawi (USAID), South Africa (CDC) under PEPFAR and Zimbabwe (USAID).

Increasing burden of diseases

The increasing burden of both communicable and non-communicable diseases is another contextual factor that catalyzed the development of PC policies in all eight countries reviewed in this study. For example, the South African policy framework and strategy highlighted that the increasing roll out of HIV/AIDS ARVs is leading to an increase in the number of children with complicated health conditions, compounded by increasing numbers of infants with cerebral palsy and other long-term illnesses and disabilities (Republic of South Africa 2017). The South African NPFSPC further states: "With the quadruple burden of disease in South Africa, an estimated 50% of all people who die in South Africa could benefit from palliative care services" (Republic of South Africa 2017, p. 10).

Likewise, in Malawi, the analysis shows that the high burden of HIV/AIDS, cancer and other NCDs also contributed to the formulation of PC policy. The Malawian National PC states:

> *The developments of this policy has come at an appropriate time when Malawi is increasingly facing enormous burden of HIV and AIDS related diseases including: cancer and other NCDs which were not adequately addressed in other existing health policies (Republic of Malawi 2014, p. 12).*

Similarly, in Rwanda, the Minister of Health articulated that the ministry is devoted to integrate PC into the Rwandan health system and that their commitment was in light of the recent increase in the incidence of chronic diseases such as HIV/AIDS and Cancer (Republic of Rwanda 2011).

The burden of communicable and non-communicable diseases is not only seen in South Africa and Malawi, but also in other African countries examined for this study (Egypt, Ghana, Zimbabwe, Swaziland, and Nigeria).

Political will

For any country to formulate a policy, both political and practical will to set aside required resources to effect policy formulation and its implementation processes are key ingredients. For example, by virtue of having an active and dedicated Steering Committee on PC appointed by the Minister of Health, South Africa saw its National Framework and Strategy for Palliative Care being approved in a short period of time, compared to previous health policies which took a long time to be passed.

In all reviewed policies government officials, especially officials from the Ministries of Health supported the development of PC and NCDs policies.

For instance, the Malawian policy states:

> *The government of Malawi has a political will to ensure that this policy is implemented and will be committed to ensure availability of adequate resources for its implementation, and to ensure this the government will work with all key stakeholders in the health sector; including but not limited to the private sector, civil society and others (Republic of Malawi 2014, p.4).*

Similarly, the South African NPFSPC states:

> *South Africa already has many resources in place to deliver palliative care services. There is a legislation and policies which support the principles of palliative care as well as an existing service delivery platform into which palliative care can be implemented (Republic of South Africa. p. 29)*

South Africa is the only country whose PC policy not only has exact and quantifiable indicators for evaluation and monitoring, but also illustrates in detail the resources required at each level of the service such as human resources, medication and consumables (Republic of South Africa 2017).

Lack of skills to deliver PPC

All the stand-alone PC policies reviewed under this study recognize the need to address skills' gaps among the PC service providers at all levels of the health care system. For example, the Malawian PC policy states:

> *Palliative care for children, adolescents and young adults shall be recognized as special requiring those with expertise in paediatric PC to take leadership in providing such care and the government shall encourage health professionals to acquire skills in paediatric PC to ensure sustainability (Republic of Malawi 2014, p. 22).*

In South Africa, lack of recognized qualified home health care workers, limited formal training, resources, lack of clear definition of roles as well as absence of curricula has been identified as major challenges to PPC provision (Republic of South Africa 2017). As such, health care providers

find it difficult to identify children's in need of palliative care. The NPFSPC states: "Nurses and other health care workers within the multi-disciplinary team receive minimal training to enable them to recognize the needs of individuals seeking assistance of PC" (Republic of South Africa 2017 p. 25).

Policy processes and actors

The policy making process involves diverse number of local, national, and international actors. Our analysis shows that while WHA resolution is one of the key drivers that many countries signed in 2014 and the pressure from Palliative Care Associations (APCAs), the national Ministries of Health led by Ministers of Health as well as a number of external and internal actors provided significant input and resources to realize such policies. We detail such actors in Table 2 below.

Table 2: Policy process and policy actors involved in the developments of policies

				Actors		
				State actors	**Non-state actors**	**International actors-largely donors**
Country	**Policy**	**Year**	**Process**			
Rwanda	PC	2011	The policy process was initiated by the Ministry of Health and Population (MOHP) and it was developed through a multi-step process of consensus building between different key stakeholders, including non-health sectors.	Minister of Health, (MoH), Permanent Secretary in the Ministry of Health	Community health workers, Physicians, Members of the community/ public, and	Mildmay International, PEPFAR, IntraHealth International, WHO, and APCA

					researchers	
Swaziland (now Eswatini)	PC	2011	The policy development was led by the MoH in collaboration with the key stakeholders such as WHO which provided technical support, other related ministries and NGOs.	Minister of Health, MoH, The House of Senate, Health Portfolio Committee, Policy and Programme Coordination Unit (PPCU), and Technical Working Group for PC, National Emergency Response Council on HIV/AIDS (NERCHA)	NGOs, Academics, Local consultants, and Editorial team	WHO and APCA
Ghana	NCD	2012	The development of NCDs policy was initiated with the joint West Africa Health Organization (WAHO) and the WHO sponsored	Minister of Health, MoH, NCD Technical Working Group, Ghana Health Service, NCD	West Africa Health Organization,	WHO

			the workshop for Anglophone West Africa in Banjul, Gambia in March-April 2010. The workshop aimed at building the capacity of country teams to develop and finalize integrated policies and action plans for NCDs prevention and control.	Control Programme Manager, Ag. Deputy Director Health Promotion, Department of GHS, Coordinator, The National School Health Education Programme, and WHO-Country Director of NCDs	Joint West Africa Health Organization (WAHO)	
Nigeria	NCD	2013	The development of the National policy and strategic plan of action on NCDs in Nigeria involved various actors, but the policy document does not give more details about how these actors	Minister of Health, Federal Ministry of Health, University of Calabar Teaching Hospital, University college of Ibadan,	Christian Association of Nigeria, Nigeria Hypertension society, Nigeria Cancer Society,	WHO, and University of Benin Teaching Hospital

			were involved in policy development process.	Zankli Medical centre, University of Abuja Teaching Hospital, National Hospital Abuja, Regional Centre for Oral Health Research and Training Initiatives (RCORTI) for Africa	Diabetes Association of Nigeria	
Malawi	PC	2014	The development of palliative care policy involved a series of consensus building meetings, consultations, and round table discussions with key stakeholders in the country.	Minister of Health, (MoH), Deputy Director of NCDs, Director of Monitoring and Evaluation, University of Malawi, Director of nursing and midwifery	Lilongwe Catholic Health Commission of Malawi, St. Gabriel Hospice, Palliative care coordinator-Ekwendeni Mission,	APCA, and USAID

				services, Dean of the nursing and PC master trainer, DMO-District Hospital, Medical council of Malawi, Kamuzu College of Nursing, and The program manager-College of Medicine	Umdozi children's PC, Civil society, and Health Equity Network, Ndimoyo PC Trust	
Zimbabwe	PC	2014	The policy process was led by the Ministry of Health and childcare (MoHCC) and included various key stakeholders.	Minister of Health and Child Care, and African University Faculty of Health Science	Hospice and PC Association of Zimbabwe (HOSPAZ), FHI360, Cancer Association of Zimbabwe, Island Hospice Zimbabwe	USAID and APCA

					Mashambanzou Care Trust, and Independent PC consultants	
Rwanda	NCD	2015		Minister of Health, MoH, and Rwanda Biomedical Center (RBC)	NGOs	WHO
Swaziland	NCD	2016	The policy process was led by the MoH in collaboration with key stakeholders such as WHO which provided technical support, other ministries and NGOs.	Minister of Health, Ministry of Health, NCDs Steering Committee, Principal Secretary	NGOs	WHO
South Africa	PC	2017	The process was led by the steering committee appointed by	Minister of Health, Ministry of Health	Community health workers, Academics,	United States Center for Disease Control

			the Minister of Health as well as the MoH.	(MoH), National Department of Health, Doctors, Alliance for Access to PC, The National Steering Committee on PC, and Director-General Health	Civil society, Researchers, Alliance for Access to PC, and NGOs working on PC issues	and Prevention (CDC) and PEPFAR
Egypt	NCD	2017	The Ministry of Health in consultation with relevant stakeholders in the health and non-health sectors, professional organizations including international agencies such as the WHO led the policy development processes.	MoH	NGOs	WHO

As the Table 2 above illustrates, our analysis of the policy process shows that both policies (PC, NCDs) underwent the same process of formulation. For example, policies from Rwanda, Swaziland, Zimbabwe, Malawi, South Africa, and Egypt were all led by the MoH in collaboration with some key stakeholders. However, most of these policies do not give much detail on how the key actors were involved in the formulation process. Although there are many actors engaged in the formulation and implementation of PC, in our analysis actors were grouped into three broad categories. These categories include:

State actors

Throughout the review of the 10 policies the Ministry of Health and Ministers of Health played the major role in developing PC policies. For example, while in South Africa multiple actors with diverse interests such as the steering committee chaired by the Members of the Executive Council (MEC) for Health in KwaZulu-Natal (KZN), which is one of nine provinces in South Africa, participated in formulating the framework and strategy for palliative care, the Minister of Health also played an important role in the process. On his foreword, the Minister of Health explained the importance of PC:

> *PC brings dignity, reduces pain and suffering and enables children and adults diagnosed with a life-threatening disease or condition to live a quality life for as long as possible. With the large disease-burden we have in South Africa, we cannot overlook the importance of integrating PC as an essential component in the continuum of health service delivery. I am confident that the implementation of this National Policy Framework and Strategy on PC 2017-2022 will not only*

increase life expectancy but will enhance the quality of the lives of children and adults who require PC services.

(Republic of South Africa 2017, p. 2).

In Rwanda we realized that only two state-level (Minister of Health, Permanent Secretary (MoH)) actors and few non-state actors (Community Health Workers, Community, Researchers) were involved in developing the policy.

Non-state actors

Non-state actors were instrumental in the formulation process of both PC and NCDs in Africa. The key actors include the associations for hospice and PC, community health care workers, civil society, NGOs, PC trusts, academics, researchers, international development agencies, Centre for Diseases Control, and community members. While reviewed policies acknowledge the engagement and support of the key actors highlighted above, none of them detailed how exactly the mentioned or acknowledged actors participated in initiating and formulating palliative care policies. Further, none of the policy documents reflected any meaningful participation of the general public in the formulation policy issues.

Beneficiaries of PPC

The analysis of the policy documents shows that very few policies involved several PC associations and NGOs (Zimbabwe, Nigeria, Malawi, and South Africa). Whilst PC associations are significant to improving PC services, none of the policies detailed on how they were involved in the policy process.

The commonly missed actors in almost all the policies, except for Rwanda, is the general community and families with individuals suffering with chronic conditions, particularly children.

Policy Content

Palliative care policies targeting children

We examined each country's policy objectives, design, and implementation strategy, as well as monitoring and evaluation indicators (Appendix 1). Out of ten reviewed policies, only 3 policies, those of Zimbabwe, South Africa and Malawi, categorically justified the need for PPC, arguing that despite having a similar philosophy to that of adult PC; children require services offered by professionals trained to do such a service. This separation is, therefore, useful to ensure children are not treated as 'small adults' (Republic of South Africa 2017, p. 17). The South African policy and strategy gave special attention to children including neonates and adolescents, as well as people with disabilities. The South African Policy Framework and Strategy states:

> *Children are vulnerable and unable to access PC due to a number of factors including their age, or developmental stage, legal status, dependence on parents or guardians, cultural norms, illness, disability, poverty, orphanhood or abandonment, lack of trained health care provider, non-availability of essential PC medicines in paediatric formulations, and distance from health services.*
>
> (Republic of South Africa 2017, p. 17)

In Zimbabwe, being the first country in Africa to establish PC services, the policy set out the need to provide PC especially to vulnerable groups: neonates, children, and people with disabilities. The policy has eight guiding principles and dedicates its fifth principle to PPC and considers family as a unit of care for the child (Republic of Zimbabwe, 2014). The policy states:

> *Every child requiring support during a life-limiting illness should have access to PC and palliative care providers should have knowledge of children's developmental stages as well as the specific requirements of PPC, including bereavement.*
>
> (Republic of Zimbabwe 2014, p. 38)

In Malawi, PC policy has included children's PC needs in its objectives, and its policy statements are very clear that children have unique needs and as such, even health care professionals must be trained to ensure they are able to provide PPC. The Malawian policy states:

> *PC for children should be delivered in a comprehensive manner and at a convenient place for the child and his or her family whenever such service is needed.*
>
> (Republic of Malawi 2014, p. 17).

In Rwanda, both policies (PC and NCDs) target the general population, including children. One of the country's policy priority intervention is to standardize the delivery of PC services for individuals with life-limiting illnesses, including children and people with disabilities, as well as developing framework to address children PC needs (Republic of Rwanda 2014). However, the policy document lack detail on how children palliative care needs are to be implemented.

NCD policies and their reference to PPC

The Nigerian NCDs policy, although focuses on the general population, it acknowledges children PC needs. In its priority interventions the policy states that, in Nigeria, children are more affected by cancer, Chronic Respiratory Diseases (CRDs), sickle cell disease (SCD) and injuries in childhood. It is on these bases that one of the NCDs policy strategic plans is to ensure that health facilities screen newborns to detect haemoglobinopathies such as sickle cell (Republic of Nigeria 2013). Also, some of the key actions included in the Nigerian NCDs policy is the need to include vaccination against carcinogenic virus such as Hepatitis-B Virus (HBV), high risk Human Papilloma Virus (HPV) serotypes, pneumococcal vaccination of children, and the use of simple and cost effective techniques for early detection of cancers (Republic of Nigeria 2013, p. 25). In addition, the policy directed the Federal Ministry of Health (FMoH) to ensure that terminally ill NCDs patients have full access to PC as well as hospice care and those patients with disabilities from complications of NCDs should receive rehabilitative care.

In Egypt, the NCD policy does pay some attention to children with chronic illnesses who require care, and in its guiding principles for action includes a life-course approach that takes into account the health and social needs at all stages of the life course and promote best practices including breastfeeding and health promotion for children (Republic of Egypt 2017, p. 15). However, the policy document does not describe care strategies for children with chronic health conditions nor does it provide guideline on how to manage pain as an aspect requiring care.

Not all PC and / or NCDs policies pay adequate attention to children's PC needs. In Swaziland (Eswatini), both policies (PC and NCDs) targeted the general population and did not really address children's PC needs. Swaziland's PC policy includes some references to PPC, and one

of its policy objectives is to ensure delivery of PC services to individuals with life-limiting illnesses, including children as part of comprehensive care (Republic of Swaziland 2011). However, there are no details on how children palliative care needs must be addressed. The NCDs policy is completely focused on adults and it does not mention children at all (Republic of Swaziland 2016).

Adherence to WHO definition of PPC

The analysis shows that five of the reviewed stand-alone PC policies adhere to the WHO definition of PPC (2002) and those policies published in 2014 onwards adopted the World Health Assembly Resolution 69.17, which calls for the member states to develop policy to strengthen PC services (World Health Assembly 2014). In a similar way, the NCDs policies adopted the WHO Global Action Plan for the Control of NCDs 2013-2020 (World Health Organization 2013) as a framework to guide policy development.

Child and family-centered approach

The reviewed policies on palliative care acknowledge the need for family-based services for children. This is because most children with life-threatening conditions are unable to access PC services and depends on adult care takers to get them to services. As such, “PPC should be centered on family-based services to allow parents to assist their children in the process” (Republic of South Africa 2017, p. 52). In Malawi, the policy emphasizes on the involvement of patients and/or their families in decision making regarding on how to manage their illness. The Malawian policy states: “A patient feels empowered enough if they are involved in the decision-making process about their care” (Republic of Malawi 2014, p.20).

Pathways to care

All policies define pathways to care. For example, South African Framework and Palliative Care Strategy clearly define pathways to care in four levels: community, primary, district/regional, and tertiary level. The policy and strategy also clearly define referral pathways to PC and recommend patients to be referred to the appropriate level of care which may be down-referral from hospital to clinic or to home for ongoing care or up-referral from clinics to hospitals for a more specialized level of care (Republic of South Africa 2017). The policy states:

"Persons in need of PC should be identified early and should be put onto a specific care pathway with clear referral processes up and down the tiers of healthcare to ensure continuity of care throughout the course of the illness" (Republic of South Africa 2017, p. 25)

Multidisciplinary teams

The analysis of policy documents further shows that the stand-alone PC policies emphasize on development and the use of multidisciplinary teams to address children PC needs. For example, the Zimbabwean policy advances the need to build a multidisciplinary team to attend to the needs of children and build effective communication to ensure every child has accessible PC. It further requires care providers to have knowledge of children's development and involve children and their family in decision-making. The policy states: "…..as with adult palliative care, a comprehensive and integrated approach from a skilled multi-disciplinary team attends to the needs of the child at all levels of care delivery (Republic of Zimbabwe, 2014 p. 38).

Indeed, the Zimbabwean policy stands out to be a policy with substantial provisions for children's needs. However, given the current economic crisis facing Zimbabwe, the extent these good provisions of the policy are implemented on the ground is unknown and beyond the scope of this study. In the South African case, the NPFSPC states: "Patients should have access to a multi-disciplinary team, including community and home-based caregivers as well as social workers and pastoral/spiritual counsellors (Republic of South Africa 2017; p. 54).

Whilst all reviewed stand-alone PC policies insisted on a multidisciplinary team in the provision of care that include health care providers, allied health professionals and social workers, in reality, most health systems in African countries do not have formal structures or mechanisms that bring individuals together within a multidisciplinary approach (Republic of South Africa 2017).

Implementation plans

The analysis of the policy documents reveals that unlike South Africa and Zimbabwe which have detailed implementation plans with indicators, the remaining policies (Malawi, Swaziland, Rwanda) have weak indicators or lack implementation plans. For example, the Malawian policy on PC have strong statements regarding M&E but the policy lack detail on how children palliative care needs are to be implemented. For example, the Malawian policy states:

> *"The main implementation agency for this policy will be the Ministry of health, in collaboration with both public and private sectors, the ministry will develop a comprehensive implementation plan that will be shared with all the relevant stakeholders" (Republic of Malawi 2014, p. 25).*

Also, the reviewed NCD policies (Egypt, Nigeria, Ghana, Rwanda, Swaziland) have detailed implementation plans, however, they lack information on how children palliative care needs will be monitored and implemented.

Budget

The reviewed policy documents reveal that, all policies included budget which will enable the implementation of PC and NCDs services, however there is no detailed information on how financial resources will be obtained and distributed to cater children palliative care needs. For example, the PC policy in Zimbabwe states: “There is a government budget allocation within the public health and social systems fiscus” (Republic of Zimbabwe 2014, p. 31).

In South Africa, one of the NPFSPC goals is to ensure appropriate allocation of financial resources to strengthen and sustain its PC program. The NPFSPC states: “South Africa already has many resources in place to deliver PC services. There is a legislation and policies which support the principles of PC as well as an existing service delivery platform into which PC can be implemented” (Republic of South Africa 2017; p. 29). The policy further highlights all the resources required to deliver PC services at different levels of health care services.

Education programmes, training and health workforce

Education programmes and training of health care providers is emphasized in all reviewed policies, which highlight the need to develop national palliative care curricula for training purposes at all levels. This will ensure the sustainability of PC services as well as bridging the gap of lack of recognized qualified health care workers to identify and deliver care to children with PC needs

(Republic of South Africa 2017). For example, the Rwandan policy on PC emphasizes on the need to train healthcare workers. It states that “the government will integrate PC training into pre-service and in-service training programs for local cadres of health workers and will ensure that health professionals have basic training in PC” (Republic of Rwanda 2011, p. 11). Moreover, the policy prioritizes the training of PC not only to health professionals but also non-professionals such as health workers, training them to deliver PC services as well as create opportunities for in-service training and continuing medical education (Republic of Rwanda 2011).

In South Africa, the policy pays significant attention on the need to train health care providers to provide different levels of PC. The South African Policy and Strategy states: “There is a need to train the multidisciplinary healthcare workforce in palliative care tailored towards meeting the unique needs of children” (Republic of South Africa 2017, p. 18). The policy further asserts the need to strengthen the existing training programmes in the country to improve PC service provision. In addition, the policy highlights:

> “*Current pre-service and in-service training programmes should be strengthened to include comprehensive PC training, and post-graduate training programmes should be developed to provide for specialists in PC”* (Republic of South Africa 2017, p. 54).

At the time the South African policy was developed, PC education programmes were offered in the undergraduate curricula of medical and nursing students. The University of Cape Town and University of Witwatersrand both have developed a PC curriculum which is embedded within the undergraduate medical curricula (Republic of South Africa 2017, p. 26).

Moreover, some of the reviewed NCD policies have included training of health care providers in their policy documents as the fundamental component. For example, the Ghana's NCD policy states:

> *"The quality of NCD-care will be improved through pre-service, post-graduate and in-service training. The introduction and expansion of training programmes in critical areas with shortage of personnel for example, nutrition, diabetics, smoking cessation, palliative care, and counselling will be supported"* (Republic of Ghana 2012, p. 21).

Monitoring and Evaluation

Of the ten policies, we observe that only the South African Policy Framework and Strategy for Palliative Care, has a concrete, measurable and impact-based strategy. In relation to PPC, the South African policy explicitly aims to establish a methodology that will enable policy implementers to identify and service children in need of PC. It names the responsible institutions – academia, the Department of Health, and other actors in the health sector – that must carry out research and provide implementable recommendations. The strategy established sources of funding and restricted the unplanned use of such resources for other activities (Republic of South Africa 2017).

Moreover, to ensure there is a strengthened PC across all levels of the health system, the South African strategy requires the formulation of National Palliative Care Guideline for adults and children as its key indicator for monitoring and evaluation (M&E). Other indicators include how many districts are offering palliative care services, how many districts in which trainers of trainees are trained, and formulating standards for care providers (such as NGOs), to ensure quality of

services. The guidelines thus specify the needs of both adults and children – simplifying both the work of service providers and families attending to their loved ones. However, at the time of writing this study the South Africa's NPFSPC policy is at the early years of its implementation, and we are therefore, unable to explain to what extent the elements of its best provisions will be executed on the ground.

In Malawi, the PC policy states: "The monitoring and evaluation strategy will ensure that PC programs are evaluated for progress and identify the strengths and weakness of the system" (Republic of Malawi 2014, p. 26). It further suggests that for effective M&E there should be an advisory panel with members from government, collaborators, PC providers, and the community. Yet, despite its strong statements on M&E, the Malawian policy is weak on details as to how such services needed by children will be identified, offered, monitored, and evaluated over time. Overall, the monitoring and evaluation section, which is only two paragraphs, is the weakest section of this, otherwise well-written, policy document.

In Zimbabwe, the policy appreciates the centrality of M&E, stating that only monitoring and evaluation can determine how far the policy is implemented on the ground. The country's policy recognizes the need to focus on its M&E on 'efficiency tracking, inputs, activities and outputs' to enable policy makers to determine whether the implementation of the policy has met its targets or not and what challenges and barriers exist (Republic of Zimbabwe 2014). The policy states: "The M&E system will enable the Ministry of Health and Child Care, and palliative care providers to successfully manage the provision of quality palliative care services" (Republic of Zimbabwe 2014, p. 46). As such, the M&E systems needs to be incorporated into all PC programmes, and one of its fundamental components of the M&E includes documentation of best practices and

sharing of experiences for PC service provision (Republic of Zimbabwe 2014). The policy assert that M&E should be participatory, involving both parents, providers and the community and should have a feedback mechanism for all stakeholders. Other policies from Rwanda, Ghana, Nigeria, Egypt and Swaziland (Eswatini) also have M&E sections in their policy documents and assert that M&E plays a vital role as it facilitates the attainment of maximum benefits in the provision of palliative care.

Discussion

In this study, we used Walt and Gilson (1994) health policy analysis triangle (HPT) as a conceptual framework to explore the current situation of PPC in Africa by examining the existing palliative care policies and assessing whether these include and sufficiently address PPC needs. The framework was particularly helpful in this study as it provided guidance in the analysis of PC policies. It enabled us to assess the content and context of selected policies as well as the policy process and actors that were involved in the formulation. The HPT has been used widely to analyze many health-related problems, and as such has influenced several health policy research in most countries around the world (Gilson and Raphael 2008). The conceptual framework is essential as it can assist policy decision-makers and health care providers to evaluate shortcomings of previous policies and plan for effective implementation of future policies (Walt et al. 2008).

Further, to understand the elements of best practices and contents of African countries' PPC, we draw lessons from successful PPC policies from HICs (Ireland, United Kingdom and Australia) – all of which have made significant progress in the provision of PPC services. These policies were used as a goldstandard to assess the retrieved policy documents from African countries. As

Downing et al (2018) argued, it is possible to provide PC services even in resource poor countries because not all services require expensive services and technologies; the use of policy documents from these countries was useful as it enabled us to understand how PPC needs are addressed in PC policies in Africa.

Our study findings show that few PC polices exist in Africa that include and address children's PC needs. Among the ten reviewed policies, no single policy targeted children alone; however, children were included in the larger population. Only three policies (South Africa, Malawi, and Zimbabwe) categorically justified and included PPC in their policy documents. Other remaining policies (Swaziland, Ghana, Rwanda, Nigeria, and Egypt) have some reference to PPC but lack detail on how PPC services are to be provided. Overall, the reviewed policies revealed that most policies targeted the general population and as such, children's needs are not adequately addressed. Whilst having policies in place is significant, the review of the literature indicate that even where PC policies are available, they predominantly focus on adults rather than on children (Downing et al. 2015; Connor et al. 2014; Caruso et al. 2014; Connor and Sisimayi 2013).

Although the official policies were only present from 2011 onwards, some countries were offering PC services prior to that. For example, despite the fact that Zimbabwe only published its Palliative Care Policy in 2014, the country has had some forms of palliative care services on offer since 1970s. One explanation for the existence of PC in Zimbabwe in the early 1970s is likely its strong socio-economic status in those days – although, the same cannot be said today due to socio-economic and political crises facing the country (Scoones 2016). In South Africa too, economic, and technological advances meant that some health facilities and services started to offer PC as

early as 1979. However, these services remain inadequate and unequally accessed across the country (Harding et al. 2018; Republic of South Africa 2017).

Whilst PC is central to persons with chronic conditions, “it is often a neglected public health issue requiring national and international responses” (May et al. 2014, p.73). The review of the general literature indicated that worldwide, there has been ongoing advocacy about the needs to improve the provision of PPC. Several international declarations were noted in the general literature that focus on children’s PC needs (see Inbadas et al. 2016). Although these declarations are essential in developing and improving access to PPC services, it is difficult to understand how many countries really work on the agreement reached in these declarations, as there is no formal accountability mechanism that require countries to report back on what they have done to improve PC on their own. Holding government accountable for the signed treaties such as the WHA resolutions on PC is been described as an important way of making them accomplishes their obligations (Downing et al.2018; World Health Assembly 2014). When PPC is acknowledged at the national level it is easier for the government to prioritize the provision of services by increasing resources such as finances as well as personnel (Downing et al. 2018).

Despite all these efforts, the review of literature also shows that currently, African countries still face acute shortages of services, especially those related to children with special needs. Harding et al. (2014) observed that children who take care of their dying parents are the most in need of specialized services, focused on psychosocial needs, rather than the usually offered physical needs. Psychosocial needs are further compounded by the associated psychological and morbidity challenges among orphans and/or children who lost one important adult care – the

father, mother or guardian. For these and many other reasons, PPC should address pre- and post-trauma period among children (Harding et al. 2014).

In our analysis, the policy documents emphasize the need of training health care professionals to offer PC services to children. This is essential, because for African countries to have a smooth implementation of PC services, continuous training of health care professionals is necessary to adhere to national standards for PC and to address children's PC needs and improve service provision. While this effort is central to having PC in place, there is a need to have broader efforts not only to train health care professionals, but also to raise public awareness about the need and availability of PPC services in the country. As Halley (2017) observed, lack of skilled professionals in health care sector in many African countries remains a challenge, not only to the PPC but also to overall health services (World Health Organization 2018).

PPC service provision needs special trainings because children have complex needs that require training of health care providers, and all people in the care of children with life threatening conditions to enable them to offer different levels of palliative care. As such, a PC competence framework 2014 was developed which describes the different levels of qualifications required for health care providers[7] (see Ryan et al. 2014).

[7] The Framework consists of three levels of PC expertise: Level one is PC approach (all health care workers), level two is general PC (nurses, doctors, allied health) and level three is specialist PC (nurses, doctors, allied health) (Ryan 2014). http://hdl.handle.net/10147/322310

There are readily available recommendations on how countries can improve training. For example, both the WHA resolution 67.19 and the Lancet Commission Report recommend that the education on PPC provide three levels of training: (1) the Palliative Care Approach; (2) General PPC; and (3) Specialist PPC (Downing et al., 2018: 6; Downing et al., 2014). Indeed, most of the reviewed policy documents consider training as a fundamental strategy to improve the provision and efficiency of PC service, and as such training has been included in implementation plans.

Our analysis also shows that PC policies in Africa are influenced by large international development agencies (donors). As Khan et al (2017) show, donor influence in a health policy happens when the recipient country relies largely on external funding due to limited domestic resources. This means that the implementation and monitoring of such a policy continues to be influenced and shaped by donors. Over reliance on donor funding in the development of health policies has been reported to be challenging to the health systems in Africa, particularly when support from donors ends (Travis et al. 2004; Ollila 2005; Khan et al. 2017). This is particularly true given the fact that PC services in Africa have been provided by NGOs and the private sector (Harding et al. 2018). This means that there are no local or domestic funds allocated to implement PC services and as such government funds will be directed to other health programs. As far as PC policies are concerned, African governments should directly finance palliative care, particularly PPC to improve service provision.

On the other hand, M&E are important aspects of any policy document because they help decision-makers to monitor and identify any key barriers to realize effective policy implementation (Judice et al. 2013; Bhuyan et al. 2010). The findings of this study show that only two stand-alone PC policies (South Africa, Zimbabwe) have strong M&E plans. The lack of adequate monitoring and evaluation mechanisms make it harder for countries to evaluate their own progress and plan for future improvement. The PC policy from South Africa and Zimbabwe set out ambitious and comprehensive indicators to ensure its efficient monitoring and evaluation. From our analytical point of view, both Zimbabwean and South African policy documents provide not only means to allow implementing agencies to review their progress but give room for external actors to assess the performance of responsible actors in the provision of PC. Although the other three reviewed PC policies (Malawi, Rwanda, Swaziland (Eswatini) have M&E sections and/or provisions, these provisions were either too general or unexplained and with weak indicators for monitoring purposes. For example, the Malawian PC policy does not provide any measurable indicators and it is, therefore, difficult to understand to what extent the policy objectives will ever be met. While the NCDs policies (Egypt, Ghana, Nigeria, Swaziland (Eswatini) and Rwanda) have detailed M&E, they lack details on how children PC needs will be monitored and evaluated over time.

Conclusion

In this study we provide an account of existing PC policies and the extent to which they address children palliative care needs in Africa. We find that the existence of specific and comprehensive policies for PPC is essential. As this and many other studies have observed, in the absence of specific policy to address PPC, there will be no meaningful plans or budgetary allocations to address this critical public health challenge. We observe that policy makers in African countries

are failing to allocate sufficient resources to palliative care policy implementation because they are more inclined to prioritize traditional and more established health services. Despite resource shortage, however, it is possible for policy makers in African states to ensure PPC services are integrated into national health programmes and policies. This would allow for an efficient allocation and use of both financial and human resources needed to deliver PPC services at all levels of health care systems in the region.

This study further indicates that the need for specific PPC is necessitated by the fact that the existing palliative care services are fragmented, offered by different actors, such as the government hospitals, health centers, NGOs, and Faith Based Organizations (FBOs) at varying levels. The presence of PC policies in few African countries provides an opportunity for policy makers to formulate specific PPC policies and relevant implementation strategies. PPC policies are needed to avoid the current blanket coverage of PC for all people and to ensure that children needs are taken more seriously in both policy and implementation strategy documents.

We argue that for African states to address the current lack of PPC policies and the associated challenges, there is a need to involve all necessary key actors in the process. This might enhance policy implementation and potentially lead to greater longer-term sustainability.

Study limitations

During and at the end of this study, the author realizes that including only policy documents published in English limited the scope of the review, as documents published in other languages could have provided some relevant evidence on PPC. Limited pre-selected key words to search for the policy documents further limited the type and number of documents to be reviewed.

Moreover, most policy documents were not publicly available online making the review process further limited. However, personal contacts with PC experts in several countries allowed the author to secure policy documents that were not publicly available.

Abbreviations

APCA African Palliative Care Association

ARV Antiretroviral therapy

ICPCN International Children's Palliative Care Network

LTH Long-Term Health conditions

MoH Ministry of Health

MoHSW Ministry of Health and Social Welfare

NCD Non-communicable Disease

NPFSPC National Policy Framework and Strategy on Palliative Care

PC Palliative Care

PPC Paediatric Palliative Care

PEPFAR US President's Emergency Plan for AIDS Relief

USCDCP United States Centre for Disease Control and Prevention

USAID United States Agency for International Development

UNICEF United Nations International Children's Emergency Fund

WHO World Health Organization

WHA Worldwide Health Alliance

Conflicts of Interests

The authors have no conflict of interest to declare in this study.

Author's Contribution

Epiphania Ngowi is responsible of the study concept, design, data collection, data analysis, drafting and final write-up of the study.

Author's Information

Epiphania Ngowi is a Master of Public Health Student specializing in Health Systems at the University of Cape Town.

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Appendixes

Appendix 1: Summary of the policy contents

Country	Tittle of the policy	Year published	Assessment Questions (Yes/No)									
			Does the policy target children, adults, or both?	Does the policy adhere to WHO definition of PPC?	Are the policy' s aims and objectives clear?	Does the policy define pathways to care	Is the policy child- and family-centered in its approach to PC?	Does the policy include multidisciplinary teams?	Does the policy provide for education programmes?	Is there enough health workforce we need for PC?	Does the policy include a budget?	Does the policy have monitoring and evaluation plan?	Does the policy have an implementation plan?
Rwanda	Rwanda National Palliative Care Policy	2011	Adults and children	yes	yes	yes	yes	yes	yes	no	yes	yes	yes

Malawi	Nigeria	Ghana	Swaziland (Eswatini)
Malawi National Palliative Care Policy	National Policy and Strategic Plan of Action on Non-Communicable Diseases (NCDs)	National Policy for Prevention and Control of Non-Communicable Diseases in Ghana	National Palliative Care Policy
2014	2013	2012	2011
Adults and children	Adults and children	Adults and children	General population
yes	no	no	
yes	yes	yes	yes
no	yes	no	yes
yes	yes	yes	no
yes	yes	yes	no
yes	yes	yes	yes
no	no	no	no
yes	yes	yes	yes
yes	yes	yes	yes
yes	yes	yes	yes

Zimbabwe	The National Palliative Care Policy	2014	Adults and children	yes	yes	yes	yes	yes	yes	no	yes	yes	no
Rwanda	Non-communicable Disease Policy	2015	General population	no	yes	yes	no	no	yes	no	yes	yes	yes
Swaziland	National Non-communicable Disease Prevention and Control Policy	2016	Adults	no	yes	no	no	no	no	no	yes	yes	yes
South Africa	National Policy Framework and Strategy on Palliative care (NPFSPC) 2017-2022	2017	Adults and children	yes	yes	yes	yes	yes	yes	no	yes	yes	yes

Egypt	National Multi-sectoral Action Plan for Prevention and Control of Non-communicable Diseases 2017-2021 (EgyptMAP-NCD)	2017	General population	no	yes	no	no	no	yes	no	yes	yes	yes

Appendix 2: Instructions for authors: Health Policy and Planning

Health Policy and Planning improves the design, implementation and evaluation of health policies in low- and middle-income countries through providing a forum for publishing high quality research and original ideas, for an audience of policy and public health researchers and practitioners. *HPP* is published 10 times a year.

HPP has a double-blinded peer-review policy. All types of papers are peer reviewed and all article abstracts from each issue are translated into French, Spanish and Chinese.

Before you submit please make sure you have followed all the relevant instructions. A checklist for authors is available on the webpage.

Not sure which section to submit to? Read our Section Summaries.

- Guidance
    i. Improving chances of publication
    ii. Manuscript format and style for all articles
    iii. Prior publication guidelines
- Types of papers
- Submission process

Guidance

Improving chances of publication

As well as the high overall quality required for publication in an international journal, authors should take into consideration:

- Addressing *HPP*'s readership: national and international policy makers, practitioners, academics and general readers with a particular interest in health policy issues and debates.
- Manuscripts that fail to set out the international debates to which the paper contributes, and to draw out policy lessons and conclusions, are more likely to be rejected, returned to the authors for redrafting prior to being reviewed, or undergo a slower acceptance process.
- Economists should note that papers accepted for publication in HPP will consider the broad policy implications of an economic analysis rather than focusing primarily on the methodological or theoretical aspects of the study.
- Public health specialists writing about a specific health problem or service should discuss the relevance of the analysis for the broader health system. Those submitting health policy analyses should draw on relevant bodies of theory in their analysis, or justify why they have not, rather than only presenting a narrative based on empirical data.
- Primarily focus on one or more low- or middle-income countries.

The editors cannot enter into correspondence about papers considered unsuitable for publication and their decision is final. Neither the editors nor the publishers accept responsibility for the views of authors expressed in their contributions. The editors reserve the right to make amendments to the papers submitted although, whenever possible, they will seek the authors'

consent to any significant changes made. The manuscript will not be returned to authors following submission unless specifically requested.

Should you require any assistance in submitting your article or have any queries, please do not hesitate to contact the editorial office at hpp.editorialoffice@oup.com.

Manuscript format and style for all articles

Only articles in English are considered for publication.

Prepare your manuscript, including tables, using a word processing program and save it as a *.doc, .rtf* or *.ps* file. Use a minimum font size of 11, double-spaced and paginated throughout including references and tables, with margins of at least 2.5 cm. The text should be left justified and not hyphenated.

The title page should contain:

- Title - please keep as concise as possible and ensure it reflects the subject matter
- Corresponding author's name, address, telephone/fax numbers and e-mail address
- Each author's affiliation and qualifications
- Keywords and an abbreviated running title
- 2-4 Key Messages, detailing concisely the main points made in the paper
- Acknowledgements
- A word count of the full article

In the acknowledgements, all sources of funding for research must be explicitly stated, including grant numbers if appropriate. Other financial and material support, specifying the nature of the support, should be acknowledged as well.

Figures should be designed using a well-known software package for standard personal computers. If a figure has been published earlier, acknowledge the original source and submit written permission from the copyright holder to reproduce the material. Colour figures are permitted but authors will be required to pay the cost of reproduction: this is currently £350 per figure.

Please be aware that the requirements for online submission and for reproduction in the journal are different: (i) for online submission and peer review, please upload your figures separately as low-resolution images (.jpg, .tif, .gif or. eps); (ii) for reproduction in the journal, you will be required after acceptance to supply high-resolution .tif files. Minimum resolutions are 300 d.p.i. for colour or tone images, and 600 d.p.i. for line drawings. We advise that you create your high-resolution images first as these can be easily converted into low-resolution images for online submission.

Figures will not be relettered by the publisher. The journal reserves the right to reduce the size of illustrative material. Any photomicrographs, electron micrographs or radiographs must be of high quality. Wherever possible, photographs should fit within the print area or within a column width. Photomicrographs should provide details of staining technique and a scale bar. Patients shown in photographs should have their identity concealed or should have given their written consent to publication. When creating figures, please make sure any embedded text is large enough to read. Many figures contain miniscule characters such as numbers on a chart or

graph. If these characters are not easily readable, they will most likely be illegible in the final version.

Certain image formats such as .jpg and .gif do not have high resolutions, so you may elect to save your figures and insert them as .tif instead.

For useful information on preparing your figures for publication, go to the Digital Art Support page.

All measures should be reported in SI units, followed (where necessary) by the traditional units in parentheses. There are two exceptions: blood pressure should be expressed in mmHg and haemoglobin in g/dl. For general guidance on the International System of Units, and some useful conversion factors, see 'The SI for the Health Professions' (WHO 1977).

Manuscript file must include text body. Title Page, Figures and Tables should be uploaded separately.

Prior Publication Policy

[Based on a statement developed by a group of editors of journals that publish articles on health, health services, and health policy. Journals currently using this statement include: Health Affairs, Health Services Research, Inquiry, Journal of Health Politics, Policy and Law, Journal of Health Services Research & Policy, Medical Care, and the Milbank Quarterly.]

Background

The policy of the journals subscribing to this statement is to consider for publication only original work that has not previously been published. Questions about what constitutes previous publication are arising with increasing frequency because of the growth of electronic publishing and the increasing number of reports and papers being produced by organizations and agencies. This statement provides guidance on this issue.

There are legitimate reasons why research may be disseminated before submission to a journal. Active communication among researchers about preliminary findings or the circulation of draft reports for discussion and critique contributes to the eventual quality of published work. In addition, organizations that support or carry our research have an understandable interest in disseminating their work. From the perspective of journals, these reasons for dissemination must be balanced against two considerations. The first is the value of the peer review process. The rules against prior publication are intended to add some assurance of the credibility of published research.

Papers are often improved during the peer review process, with findings, conclusions, and recommendations sometimes changed in response to reviewers' comments. The public and policymakers might be confused or misled if there were multiple versions of a paper in the public domain. Second, from a more parochial viewpoint, journal space is limited, and much time and expense are involved in the evaluation, publication, and distribution of journal articles. Journals must make difficult choices about what to include; there is less value in publishing papers that have already been disseminated to their target audiences.

We discuss here several types of dissemination and provide guidelines with respect to the prior publication question. This discussion is essentially an elaboration of two rules, the first emphasizing previous dissemination of the material, the second stressing disclosure.

- Rule One: If the material in a paper has already been disseminated to a journal's audience, particularly in a format that appears to be a final product, then it is unlikely that a second version will be worth publishing in the journal.
- Rule Two: It is the responsibility of authors to let editors know at the time of submission whether a paper's contents have been previously disseminated in any manner so that the editors can determine whether to proceed with the review process.

Previous Presentations at Meetings

Presentation of a paper at conferences or seminars usually does not jeopardize the possibility of publication.

Working Papers

Dissemination of "working papers" to a limited audience will not ordinarily jeopardize publication. Working paper series are used by many organizations as a means of enabling researchers to obtain critiques from fellow researchers. Working papers covered by this policy are those that are released by the author or an organization rather than by a publisher, are not advertised to the public, and are marked as drafts that are subject to future revision. HPP will not publish papers for which a similar working paper is already available in the public domain.

Internet Postings

Release via the Internet may jeopardize journal publication under some circumstances.

Presentation of the work as a final report is a marker of an attempt to reach a wide audience, particularly when combined with efforts to direct traffic to the work (e.g., via links on other sites) and efforts to attract attention (e.g., press releases). In contrast, if a document is posted on the Internet only to facilitate communication among colleagues with the aim of getting feedback, and if there has been no attempt to otherwise attract the attention of journalists, the public, or the broader research community to the document, then this is unlikely to preclude journal publication.

In general, when posting on the Internet serves similar functions as presentation at professional meetings - facilitating the development of papers and the improvement of the research, influencing future revisions, and not constituting a "finished" product - it would not be considered prior publication. On the other hand, when the Web site posting functions as a virtual version of a conventional publication, which may even be copyrighted by the posting organization, the benefit of an additional publication in the journal will be scrutinized carefully.

In cases where there has been little to no exposure at the time that a paper has been submitted to the journal, but the circumstances surrounding the posting make it likely that a high level of exposure (press coverage, etc.) might occur, then the author should remove a posting as a condition for further consideration of the manuscript.

Authors who post papers on a Web site and do not want it to constitute prior publication should also post a disclosure statement such as: "This draft paper is intended for review and comments only. It is not intended for citation, quotation, or other use in any form." This statement should be kept on the Web site throughout the review process and until the paper is actually accepted for publication in a journal. Once accepted, authors should post a message to the effect that: "A

revised final version of this paper will appear in (Journal Name), volume, issue." Authors also should include this statement as a header or footer on every page of the paper.

Formal Reports from Foundations, Academic Institutions, Institutes, Trade Associations, and Government Agencies

The dissemination efforts of foundations, government agencies, research institutes, and other organizations that support or carry out research can complement publication in peer-reviewed journals. If publication in one of our peer-reviewed journals is desired, organizational publications should be timed to coincide with or follow journal publication, with appropriate copyright permissions having been obtained. This sequence ensures that the peer-review process will have an opportunity to correct deficiencies of method or presentation.
Formal, published reports that have gone through an editorial process, that have been intended to reach a wide audience, and that are publicized and available to any interested party (whether free or not) usually will not be considered for journal publication. A paper that is based on such a report might be considered for publication if it were sufficiently different in emphasis or intent. In such instances, the author should explain at the time of submission (or before) how the paper differs from the previously released report and why its publication would represent a distinct and important contribution beyond that version.

Policy briefs

If the findings of a piece of research have been published locally (i.e. in a specific country) with the aim of influencing policy debates in that country then even if the brief is available on the web

we may consider publishing an article so long as (i) the brief has not had wide circulation outside the country and (ii) the brief is clearly targeted at policy-making audiences, and hence does not include the detailed discussion of methods and perhaps findings that one might expect in a journal article.

Media Publicity

If results reported in a working paper have become widely known as a result of media exposure (or even if the potential for widespread exposure remains during review), and that working paper is readily available to interested readers (e.g., through a Web site), an editorial judgment will be made whether journal publication would be appropriate. Authors can help protect their work from unwanted media exposure by making clear on working drafts, copies presented at conferences, and other versions that it is a draft that has not yet undergone peer review for publication and that findings and conclusions are subject to change. Authors also should request that any "stories" derived from interviews with the media be embargoed until the work is published or released by the publisher (see, for example, Fontanarosa, P.B., and C.D. DeAngelis. 2002. The Importance of the Journal Embargo. Journal of the American Medical Association 288: 748-750). Any accepted manuscript released to the media should contain the statement: "A revised final version of this paper will appear in (Journal Name), volume, issue." Journal policies involving author contact with members of the media may vary, depending on the issue or journal. Thus, authors should check with the editor before speaking with or distributing papers to members of the media.

Importance of Disclosure

In contrast to the editors' decision whether a certain paper has been disseminated too widely to warrant journal publication, there is very little judgment involved in whether an author should disclose previous dissemination. Prior to, or at the time of, submission of a paper that has been disseminated in any of the ways discussed previously, authors should bring this to the attention of the editor so that a determination can be made before the paper goes into the peer-review process. In so doing, authors should describe in what form and how the work was previously disseminated and how the submitted manuscript differs from previously disseminated versions. Editors might be receptive to a modified version of a paper that has been widely disseminated if the submitted version has a different focus (e.g., more emphasis on methods, more sophisticated analytic approach, or discussion of developments that have transpired since the initial dissemination). The key point is to let editors know about any dissemination that will have, or is likely to have, occurred before the journal article is published rather than have it discovered during or after the review or editorial process. As part of the submittal, authors should include copies of other related papers that might be seen as covering the same material.

Failure to disclose could preclude publication in the journal or, if already published, could result in a notice in the journal about the failure and may result in a retraction of the article.

Manuscript Preparation

Page 1: *Title Page* – as above.

Page 2: *Abstract.* The abstract should be prepared in one paragraph, no headings are required. It should describe the purpose, materials and methods, results, and conclusion in a single paragraph no longer than 300 words without line feeds.

Page 3: *Introduction.* The Introduction should state the purpose of the investigation and give a short review of the pertinent literature, and be followed by:

Materials and methods. The Materials and methods section should follow the Introduction and should provide enough information to permit repetition of the experimental work. For particular chemicals or equipment, the name and location of the supplier should be given in parentheses.

Results. The Results section should describe the outcome of the study. Data should be presented as concisely as possible, if appropriate in the form of tables or figures, although very large tables should be avoided.

Discussion. The Discussion should be an interpretation of the results and their significance with reference to work by other authors.

Abbreviations. Non-standard abbreviations should be defined at the first occurrence and introduced only where multiple use is made. Authors should not use abbreviations in headings.

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Health Policy and Planning welcomes submissions of the following article types:

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- Methodological musings
- Innovation and practice reports
- Commentaries
- 'How to do (or not to do)...' [for example, see Hutton & Baltussen, HPP, 20(4): 252-9] and
- '10 best resources' [for example, see David & Haberlen, HPP, 20(4): 260-3].

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Manuscripts should preferably be a *maximum* of *6,000* words, excluding tables and figures/diagrams.

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